Promoting the Use of **Patient-Reported Outcome Measures**

PRACTICAL TOOLS FOR **CONSUMERS** AND **PURCHASERS**

Consumer-Purchaser
ALLIANCE
Better information. Better decisions. Better health care.

Contents

Preface

This toolkit is intended to support consumer and purchaser advocacy of high-value patient-reported outcome measures (PROMs) and patient-reported outcome performance measures (PRO-PMs) in clinical practice, for consumer choice, and for provider payment.

The Advocacy Guide describes Consumer-Purchaser Alliance's proven advocacy strategies for advancing widespread adoption and use of PROMs and PRO-PMs, offers effective responses to common assertions made in opposition to the use of PROMs, and provides examples of successful implementation.

The Selection Guide allows advocates to quickly understand which PRO tools, of the hundreds that are available, (1) are ready for use in clinical practice and (2) meet the needs of consumers and purchasers — to support advocates in making specific PROM/PRO-PM recommendations for a given condition. The Selection Guide covers **general health status** and six high-impact clinical conditions: **asthma**, **depression**, **coronary artery disease**, **heart failure**, **hip replacement**, and **knee replacement**. The PROMs and PRO-PMs included in this guide were chosen based on the following selection factors: (1) included in existing value-based purchasing and public reporting programs; (2) commonly used in clinical practice; (3) found in established measure sets such as the Core Quality Measures Collaborative (CQMC), Minnesota Community Measurement, and the International Consortium for Health Outcomes Measurement (ICHOM) standard sets; and/or (4) regarded highly by consumers, purchasers, and other major stakeholders in multi-stakeholder forums (e.g., the National Quality Forum, the Measure Applications Partnership).

Please note that only three of the five conditions covered in the selection guide (asthma, depression, and knee replacement) have PRO-PMs available.

Glossary

Clinical Health Data and Outcome Measures

Clinical outcome measures provide information on the results of clinical procedures, hospital admissions and other health care interventions and are based on data gathered from clinical sources or insurance claims, not from patients themselves. Examples include mortality rates, infection rates, readmission rates, etc.. Clinical outcomes are useful for understanding the results of clinical practice but often do not capture health outcomes that are central to a patient's health and wellbeing, such as functional status and pain levels.

Patient-Generated Health Data

Patient-generated health data (PGHD) is an emerging term used to describe health data that are created, recorded, or gathered by or from patients (or caregivers) to help track and improve the patient's health and health care. This can include health history, biometric data, self-reported functional status, symptom burden and experience of care. Going beyond clinical indicators and treatment history, PGHD allows a physician to develop a more comprehensive understanding of his or her patient. For example, PROMs provide information about the impact of care from the patient's perspective.

The source of PGHD must be patients (or caregivers) – not providers – who voluntarily participate in the sharing of their experiences and perspectives. PGHD collection methods include standardized surveys (administered independently or via care coordinators/navigators), patient portals, mobile apps, and remote health monitoring devices.

Patient Experience

Measures of patient experience do not fall into the classic definition of outcomes (e.g., complications or mortality). Rather, they assess the experience of care from the patient's perspective, focusing on aspects of care delivery such as timeliness, communication, coordination, pain management, and respect for patient preferences.

Both patient-reported outcomes and patient experience are types of patient-generated data. Patient experience is an important indicator of care quality in its own right and has been linked to improved clinical outcomes.[1] Understanding patients' experiences can help providers to better address patient needs, for example, by revealing specific barriers to patient engagement. Patient experience data should be routinely collected and used to improve care delivery and support system transformation.

Patient-Reported Outcomes

Patient-reported outcome (PRO) information is a type of a patient-generated data that focuses on key aspects of a patient's social, emotional, and physical wellbeing and cannot be obtained from other sources. The information comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else on the care team. For example, patients are the experts on how well they can function (e.g., climbing stairs), their experience of symptoms (e.g., fatigue, nausea, pain), and their emotional state (e.g., confused, anxious, depressed).

Patient-Reported Outcome (PRO) tools

PRO tools are standardized surveys administered to patients to capture important information, e.g., the status of a patient's health at a given time. Patient-reported outcome measures and performance measures are built on the administration of PRO tools to a patient at least twice over a clinically meaningful period of time.

Before the information obtained from a PRO tool can be used in clinical practice to provide insights on a patient's change in health status, the PRO tool must be tested to show validity (i.e. assesses the specified health concept), reliability (i.e. the degree to which different raters give consistent estimates of the same health status) and responsiveness (i.e. ability of questionnaire to detect meaningful changes in health status over time).

PRO measures (PROMs)

PROMs are built on the administration of a PRO tool twice over a clinically meaningful period of time in order to solicit data on a patient's change in health status. PROMs can be used to assess whether and how a patient's health status has changed over time as a result of treatment, services and other strategies and can sometimes be used to compare two patients' change in health status (depending on the PROM). However, PROMs alone cannot be used to determine the effectiveness of providers at improving health status because risk-adjustment methodologies for PROMs do not account for a patient's expected health status (see PRO performance measures).

PROMs are tested to determine minimal clinically important differences (MIDs), which are often presented as a raw survey score or a range of survey scores. MIDs are used to determine whether a meaningful improvement or achievement in health status has occurred (e.g., a 10 point change in score indicates a patient's health status has improved meaningfully, a score of at least 150 indicates a patient has returned to or achieved full functioning).[2] Widely used PROMs often have MIDs specific to various segments of the patient population and other benchmarking tools to further facilitate the interpretation of scores (e.g., survey score norms for particular patient populations, peer benchmarking data). Benchmarks are identified through statistical testing of PROMs data and improve as additional data are made available.

PRO performance measures (PRO-PMs)

The primary distinction between a PROM and a PRO-PM is in the appropriate uses of the information provided. PRO-PMs go further than PROMs by attributing performance to a provider entity (or treatment) through the application of risk-adjusted performance benchmarks (i.e. expected health status targets given a patient's health profile). For example, a patient with multiple chronic conditions would not be expected to achieve the same health status following treatment as a patient with no comorbidities. Because each patient's expected health status target is factored into the PRO-PM results through robust risk-adjustment methodologies, PRO-PMs can be used to calculate the impact of treatment, services and other care strategies and are suitable for accountability purposes.

[2] Minimal clinically important differences vary by population and context.

Introduction

The concept of patient-centeredness has become a North Star for U.S. health system reforms and innovation since its inclusion in the Institute of Medicine's "quality chasm" report as one of six key elements of high-quality care.[3] Consumers and purchasers profoundly agree that the provision of patient-centered care should be a central goal for all healthcare settings, as it is characterized by active patient-provider partnerships in developing and carrying out comprehensive and customized care plans (e.g., care coordination, shared decision-making, shared goal-setting). This foundational shift in the focus of care delivery demands a parallel shift in the performance measurement enterprise. Historically, measurement has focused on clinical indicators of health (e.g., blood pressure) which provide little information on outcomes that matter to patients (e.g., quality of life).[4] **Patient-reported outcome (PRO) data capture a new dimension of care quality by asking patients to self-report the impact of care/treatment in ways that matter to them (and to providers and society): improved functioning, reduced pain, and improved quality of life.**

In virtually every other service industry, consumer input is highly sought-after — often factored into decision-making processes across all levels of an organization — and the focus is on meeting customers' individual needs and ensuring positive experiences. The Consumer-Purchaser Alliance firmly believes this goal should be shared by the health care industry. The widespread collection and use of PRO data in clinical practice would allow providers and other healthcare stakeholders to understand how different treatment protocols and care practices impact a patient's functional status, symptom burden, and psychosocial health, representing a fundamental shift in the focus of care delivery to account for outcomes that truly matter to patients. Moreover, it would ensure that patients' perspectives play a substantial role in any "value of care" assessments and that health system transformation is anchored in the aim to improve outcomes that are important to patients and their experience of care. PROs have gained some notoriety over the last decade for their unique value to assessments of clinical quality, as evidenced by the establishment of the Patient-Centered Outcomes Research Institute (PCORI),[5] the development of Patient-Reported Outcomes Measurement Information System (PROMIS) measures,[6] and the emphasis on PROs in the Medicare Access and Chip Reauthorization Act of 2015 (MACRA).[7]

The widespread collection and use of PRO data in clinical care represents a fundamental shift in the focus of care delivery, ensuring that patients' perspectives play a substantial role in any value-of-care assessment and that health system transformation is anchored in the aim to improve outcomes that are important to patients.

[4] For brevity, we refer throughout this document to "patient" and "care," given that the application of PROs and PROMs in this toolkit is rooted in the medical model, e.g., as part of one-time or ongoing treatment by a clinician. To some, these terms could imply a focus on episodes of illness and exclusive dependency on professionals. This can seem to be at odds with one underlying goal: to improve patient and family engagement and promote shared care planning. Any effort to achieve these goals must include the use of terminology that also resonates with the numerous consumer perspectives not adequately reflected by medical model terminology. For example, people with disabilities frequently refer to themselves as "consumers" or merely "persons" (rather than patients). Similarly, the health care community uses the terminology "caregivers" and "care plans," while the independent living movement may refer to "peer support" and "integrated person-centered planning."

Consumers and purchasers have long-advocated for the collection and use of PRO data in clinical practice. However adoption in the United States is largely voluntary and therefore, is often isolated to individual health systems or quality improvement networks (e.g., Partners' Health, Minnesota Community Measurement). Other countries such as the UK, the Netherlands, and Sweden are collecting these data on a national scale. Such initiatives have demonstrated that the use of PROs in clinical care can enhance shared decision-making, improve the precision of indications for undergoing surgery, and enhance monitoring of complications and patient health status when a patient leaves the health care setting.[8] Moreover, by serving as a formal channel in routine care for soliciting patient perspectives on key aspects of health and well-being, the collection and use of PROs can also prompt discussions about sensitive issues that otherwise would not have occurred and can allow providers to detect and respond to early signs of disease recurrence or declines in health.

In multi-stakeholder advocacy settings, consumers and purchasers are often the torchbearers for the use of PROs and must persuade other health care stakeholders about the importance and feasibility of PROs implementation. Given the U.S.'s current voluntary environment for PROs collection, it is essential that consumers and purchasers emphasize the value of PRO information for providers in improving outcomes that matter to patients and delivering patient-centered care. The Toolkit's Advocacy Guide offers high-level advocacy strategies and provides effective responses to common assertions opposing PROs implementation, in order to facilitate consistent messaging about the importance of PROs (e.g., to policy makers, in multi-stakeholder settings).

Another common challenge for consumer and purchaser advocates is determining which specific patient-reported outcome measures (PROMs) to promote for use in clinical practice, as many are of variable psychometric quality, and most of the PRO survey tools available were developed to answer (one or a few) specific clinical research questions.[9] Yet, even narrowing the search to those PROMs that meet minimum standards for validity, reliability, and responsiveness would reveal a list of hundreds for the conditions covered in this guide.[10] The Toolkit's Selection Guide is intended to support consumers and purchasers in selecting specific high-value PROMs to promote for adoption in clinical practice and does not comprise an exhaustive list of PROMs for any clinical area. The Selection Guide offers Consumer-Purchaser Alliance's recommendations for each condition and provides an overview of other commonly used PROMs/PRO-PMs in the United States, in order to promote awareness of and alignment on specific high-value PROMs/patient-reported outcome performance measures (PRO-PMs).

[9] Many PRO tools available were designed for clinical research purposes and are not suitable for use in clinical care. In clinical research, PRO tools are often used to track changes in a single patient's health status, to determine a patient's eligibility in a clinical trial, or to confirm other clinical observations about a patient's health status. In order to develop a PROM/PRO-PM from a PRO tool for evaluation of provider/treatment efficacy, the PRO tool must first be validated for responsiveness to differences/changes in health status and must have interpretation guidelines (i.e. defined minimal clinically important differences, indicating the minimum change in score that reflects a meaningful change in health status to the patient).

[10] There are so few PRO-PMs that when one is available, we always recommend prioritizing and advocating for the available PRO-PM. Selection of PRO-PMs is not challenging in the same way as selection of PROMs because there are so few currently available.

Advocacy Guide

While the importance of patient-reported outcome (PRO) information has long been understood by consumers and purchasers (who desperately need this information), other healthcare stakeholders have varying degrees of understanding and acceptance of the critical importance of collecting and using PROM/PRO-PM data in clinical practice. This advocacy guide describes Consumer-Purchaser Alliance's proven advocacy strategies, common claims other stakeholders make against the adoption of patient-reported outcome measures (PROMs)/patient-reported outcome performance measures (PRO-PMs), and examples of successful implementation. It is critical that consumers and purchasers continue to staunchly advocate for the widespread adoption of PROs in clinical practice as these data are still gaining recognition and acceptance.

The Consumer-Purchaser Alliance has traditionally focused its advocacy efforts on encouraging CMS, as the largest healthcare purchaser, to incorporate PROMs and PRO-PMs into its payment and public reporting programs. For example, the Comprehensive Care Joint Replacement Model carves out a portion of the quality score (10%) for collecting and reporting PROMs data (i.e., providers who do not submit data on PROMs to CMS can only achieve a maximum quality score of 90%). State purchasers also have significant potential to advance the use of PRO information. The state of Minnesota publicly reports results at the medical group level on a standardized set of performance measures, which includes PROMs. Commercial health plans and other purchasers (e.g., self-insured employers) also have unique leverage with providers, often using financial incentives to influence care delivery and prioritization of quality improvement activities. Other high-impact venues for PROMs/PRO-PMs advocacy include clinical data registries and multi-stakeholder settings such as the National Quality Forum (NQF).

High-Level Strategies

➔ Educate other stakeholders and policymakers about the value of PRO information, particularly in clinical care to support patient-centered quality improvement initiatives and the delivery of patient-centered care

Any assessment of the performance of health services and/or systems should include patients' perspectives on the impact of care provided. Despite general agreement with this principle, patients are rarely, if ever, systematically asked to report whether the care they received made a difference in their lives. Given the U.S.'s current voluntary PROs reporting environment, it is critical that consumer and purchaser advocates emphasize the value of PRO information in clinical care.

The following are high-level talking points on the unique value of PROs:

- PRO data provide a more holistic picture of a patient's health status by uniquely assessing outcomes of care and treatment that are central to a patient's physical, social, and emotional wellbeing. In other words, PRO information helps providers understand how care and treatment are impacting patients' day-to-day lives. This information must be volunteered by the patient and therefore, cannot be captured by traditional clinical outcome measures.
- Widespread collection (and public reporting) of PRO data would allow for comparisons of providers and treatment options on aspects of quality that are important to patients (e.g., which provider/treatment is best at managing pain or improving functional status), enabling a more informed choice for consumers based on his or her individual priorities. For example, functional status data on the differential impact of various treatment options for patients with similar health profiles would bring the shared decision-making process out of the abstract and enable a more robust patient-provider discussion about how each treatment option would or would not meet the patient's medical needs and personal priorities.
- At a high-level, PROs can support our evolution towards a more patient-centered high-value health care system because PROMs and PRO-PMs capture the degree to which a health service or system is meeting the individual needs of patients. PROs collection provides data for providers to drive more tailored quality improvement strategies while also supporting the delivery of patient-centered care that is built on a foundation of shared decision-making and goal-setting.

The following are specific examples of how PROs promote high-quality clinical care:

- **PROMs/PRO-PM data can improve the processes and outcomes of care.**

  At the point of care, the systematic use of PROMs/PRO-PMs can serve as a formal channel for soliciting patient perspectives on key aspects of health. Many clinical encounters already include discussions of these concerns, but are neither in a standardized format nor systematically captured. The results of PROMs/PRO-PMs can give providers a new or more objective awareness of trends in patients' health status and symptoms, the effectiveness of care provided, and their own performance as it relates to other providers. When systematically tracked, PROM/PRO-PM data can help providers detect and respond to early signs of disease recurrence or declines in health. Moreover, systematic use of PROMs/PRO-PMs can improve care by prompting discussions about sensitive issues that otherwise would not have occurred.

  Lastly, of note — the Health Care Payment Learning & Action Network (HCP-LAN) White Paper on Clinical Episode Payment Models[11] offers another example of how PROs can improve care, recommending the use of PROMs in determining whether or not to undergo an elective hip/knee procedure (i.e., baseline functional status is recommended as a factor in the decision of whether or not to enter into an elective hip/knee episode).

- **The collection and use PRO information contributes to a culture of patient-centered care.**

  PROMS/PRO-PMS enable providers to deliver more personalized medicine. Some patients have a greater need to understand how treatment decisions affect overall health and quality of life and may uniquely benefit from

the collection and use of PRO information — for example, cancer patients for whom treatment is often many years long, patients with permanent functional impairments, or patients with degenerative diseases for whom goals of treatment are to slow progression of the disease. Providers who treat patients with such conditions need information (beyond clinical indicators of health) on functional status, quality of life, and self-care capabilities to track and better understand how treatment is impacting their patients' health and daily lives.

PROMs/PRO-PMs can also be used to initiate and/or support shared care planning and goal setting by 1) prompting discussions about the unique needs of each patient and the degree to which care provided is meeting those needs; and 2) tracking progress on a patient's individual goals which very often go beyond achieving positive clinical indicators of health. For example, a provider may change the course of treatment if a patient's longitudinal PRO data indicates that care is not meeting the goals of their shared care plan. In the long-run, widespread collection of PRO data would enhance shared decision-making by providing information on important outcomes of care for patients. For example, aggregated PRO-PM data on the recovery profiles of two different courses of treatment would provide a more meaningful understanding of the risks and benefits associated with each treatment.

- **Administration of PRO survey tools prior to the patient-provider encounter can enhance workflow efficiency and save providers valuable face time with patients.**
  Partners HealthCare, a large multi-hospital system in Boston, reports that administering PRO survey tools to patients in the waiting room allows doctors to use limited visit time to hone in on the most troubling aspects of a patient's health status and "explore symptom burden and treatment preferences in a deeper, more focused way."[12] Without the use of PRO surveys, providers may need to spend time administering verbal checklists during the visit.

- **Collection of PRO information can allow clinicians and facilities to differentiate themselves as a patient-focused provider.**
  Use of PROMs and PRO-PMs improve the ability of providers to delivery value-based care. Providers who collect this information are able to launch quality improvement initiatives on aspects of care delivery that are undetectable to providers who have not yet incorporated PRO data collection into their practices. It is only a matter of time before more PRO-PMs are included in payment and public reporting programs, as evidenced by the emphasis on PROs in the Medicare Access and Chip Reauthorization Act of 2015 (MACRA) and in the Measure Development Plan.

➔ Push for the inclusion of PRO data collection in all provider quality incentive programs

In the current landscape, patient-reported outcome information is not being collected widely and PRO-PMs do not exist for most conditions.[13] However, all provider payment and public reporting programs should incentivize PROs adoption to send a clear signal to providers that high-quality care necessitates the collection and use of PRO data. It is only

[13] The majority of robust, validated tools that assess specific phenomena related to health and well-being were developed for the purpose of clinical research, not for use in clinical care.

appropriate to reward a provider for superior outcomes based on PRO-PM results, not PROM results (i.e., payment should only be tied to PRO-PM results, not PROM results). When well-validated PRO-PMs are not available for a given condition, Consumer-Purchaser Alliance recommends advocates push for mandatory reporting or pay-for-reporting of PROMs data to reinforce their importance in improving clinical practice. For example, a pay-for-reporting program design could require that providers achieve a minimum response rate to get "credit". Pay-for-reporting/mandatory reporting of PROMs encourages providers to invest early in the data infrastructure and practices changes that must accompany successful use of PROs data in clinical care to support patient-centered care.

Furthermore, PRO data collection should not be siloed as a performance measurement activity, but rather adopted as a one of many levers in a more comprehensive effort to drive patient-centered care and better outcomes. PROs data collection encourages provider-patient discussions to focus more on outcomes that matter to patients but must be implemented with other practices changes and educational/awareness campaigns to be successful. A commitment to change practice patterns/culture, for example, could include discussing the results of PRO surveys at each patient encounter or reviewing historical trends when making shared decisions. These types of changes that make PROs more central in the provider-patient conversation also serve to enhance survey response rates and data completeness.[14]

HOW IS PRO DATA COLLECTED?

Patient-reported outcome (PRO) data are obtained through the administration of standardized surveys — commonly referred to as PRO survey tools or, simply, PRO tools. Depending on the nature of the condition and the patient's health status, PRO tools are completed by the patient and/or caregiver. Advances in digital health technologies offer new ways to collect PRO data electronically and in real-time.

PRO tools can be administered in many ways: as part of a visit (e.g., completing surveys on a tablet or paper in the waiting room) or at home (e.g., as a routine part of follow-up care after surgery) by paper mail, via an online portal, via a phone call, or via text message. Some PRO tools, such as the Patient-Reported Outcomes Measurement Information System (PROMIS), are available in computer adaptive testing (CAT) formats in which a computer administers the survey and selects each new survey question based on answers to previous questions i.e., questions administered are tailored to a patient's ability or symptom level.

Factors influencing the cost and speed of administration include technology, workflow, and use of outside vendors. The results from PRO tools are typically risk adjusted (e.g., for age, severity of the primary clinical condition) so other data elements often need to be collected from administrative claims, EHRs, and/or medical records.

Obtaining PRO information without efficient systems in place can be burdensome to patients and providers, affecting survey response rates and the ability to capture longitudinal information. Short-form questionnaires have a reduced number of survey questions and are known to improve patient compliance, response rate, and the quality of response.[15] A short-form PROM will have undergone robust psychometric testing to ensure that it assesses the same constructs of health status as its long-form counterpart. However, the information obtained can be slightly less reliable because of the reduced number of questions. **The Consumer-Purchaser Alliance accepts the trade-offs associated with short-form PROMs and generally recommends these versions when available, as a strategy to improve patient response rates and ease of administration (i.e. improves provider adoption rates).**

➔ Emphasize the importance of PROMs reporting alignment for developing new PRO-PMs

The Consumer-Purchaser Alliance strongly encourages advocates to promote the adoption of PROMs and PRO-PMs that are already more commonly used in clinical practice settings to accelerate the development of new and improved PRO-PMs. The use of a PROM in clinical practice is an important precursor in the development of a corresponding PRO-PM because such use increases the amount of data available for stasticial testing. For the same reason, greater use of an existing PRO-PM will enhance its benchmarking and other analytic capabilities (e.g., benchmarking by patient comorbidity, state-level benchmarking). Those advanced institutions currently collecting PRO data often assess the same aspects of quality but use slightly different survey tools or approaches to data collection, representing a missed opportunity to accelerate the development of new PROMs and PRO-PMs.

Clinical data registries have significant potential to maximize the impact of reporting alignment among various health systems/provider groups to advance the field of PRO-PMs. Registries have robust data collection infrastructure in place and the ability to integrate patient-level EHR data with other types of data. For example, a national registry could collect data from providers and health systems all across the country and aggregate such data to facilitate PRO-PM testing or other benchmarking capabilities.

Common Objections & Consumer-Purchaser Alliance Responses

CLAIM: "It's not fair to hold providers accountable for patient-reported outcomes (PROs)."

RESPONSE: Patients' perspectives on care quality and outcomes must play a central role in how 'value' is defined in our health care system. Assessments of care quality should not be considered complete unless patients have contributed their perspective – therefore, to hold providers accountable for high-quality care is to hold them accountable for the results of PRO-PMs.

Providers often, and correctly, argue that health outcomes can be influenced by factors other than treatment and services rendered by a provider (patient behavior or social determinants of health, for example). However, this should not preclude using outcome measures, including patient-reported outcome measures, to assess providers. Often, providers are trusted advisors and have strong influence over their patients' behavior. For example, research has found that when providers offer counseling, patients are more likely to implement healthy changes, such as increased physical activity, improved nutrition, and smoking cessation.[16,17] Conversely, when patients have a limited understanding of their conditions and the importance of lifestyle adjustments, they are less likely to initiate and sustain these changes.[18] In addition to providing robust health education, physicians are optimally positioned to connect patients with community and social support services that can address social determinants of health. Moreover, many other industries face a similar measurement challenge in which multiple factors influence an outcome (e.g., a commercial airline's average on-time record is affected by weather conditions).

CLAIM: "PRO data collection is too burdensome/costly."

RESPONSE: All types of measurement pose data collection challenges. However, Consumer-Purchaser Alliance strongly emphasizes the importance of balancing data collection effort with the value of the information provided. The foundational importance of patient-reported outcomes in providing high-quality patient-centered care delivery (see above) makes the investment in PROs data collection infrastructure worthwhile. Examples of successful PROs implementation are described in the following section. Challenges specific to administration of PRO survey tools are described below, for your reference.

Provider Engagement: Provider engagement in PROs collection is very important as evidence shows that providers who talk with their patients about the importance of patient-reported outcomes to their care are likely to have greater patient participation.[19] It is even more crucial that providers discuss the results of PRO surveys with patients and use such discussions to better tailor the patient's care plan to his or her individual needs, to clearly demonstrate how completion of PRO surveys is useful in improving care. Doctors may be reluctant to utilize patient surveys due to limited office visit time. However, it is not necessary for the provider to administer PRO surveys and in fact, this activity is more appropriate for a care coordinator/navigator (prior to the patient-pro-

vider encounter) given that the provider's performance is a significant factor in the patient's evaluation of any outcomes of care.

Survey Cost and Administration: Cost to the provider is determined largely by the administration method, in addition to the potential cost of using the PRO tool itself (see Proprietary PROMs & PRO-PMs box).[20] Electronic survey administration (e.g., email, iPads, patient portals or computer kiosks) costs less than paper-based administration and requires fewer staff resources. Administration of paper-based surveys can require significant time and resources for printing, mailing, and ensuring data integrity. Collection of PRO data requires significant staff time, however, best practices are available on maximizing efficiency and reducing the amount of staff resources necessary.[21]

Limitations of Electronic Survey Administration: Collecting surveys using email and other electronic means may be limited if email addresses are not systematically collected and maintained. Email solicitations can also get caught in email spam filters, and some patients may have limited access to a computer.

Data Governance: There is limited guidance on data governance and transfer of PRO surveys between clinical research and QI, as well as a lack of guidance on interpreting HIPAA regulations surrounding settings and modes of PRO data collection.

PROPRIETARY PROMS & PRO-PMS

The use of proprietary surveys requires a license from the survey developer to use, representing an additional cost to the provider beyond the costs of survey administration.[22] These licensing and other associated fees may be a one-time cost or a cost per use arrangement (in which case, volume discounts are frequently available). The licensing agreement often includes analytic and other benchmarking tools that enhance the utility of the survey data obtained. For example, the SF-36 and SF-12 surveys (managed by Optum) come with access to survey score norms for patients with specific medical conditions that allow providers to better interpret patient survey scores and understand their own performance.

The costs associated with proprietary PROMs and PRO-PMs is a significant practical issue confronting those who wish to collect and use PROM data. These costs pose a barrier to widespread PROM data collection in registries, including qualified clinical data registries,[23] and other quality reporting mechanisms as providers will generally not be required to report on an expensive PROM or PRO-PM as a condition of participation. Furthermore, proprietary surveys may slow progress in developing new PRO-PMs. Ideally, for PRO-PM development efforts, all providers would report on the same PROM (or PROMs within an established cross-walk) for each condition. If a provider has begun to use a proprietary PROM, that investment can be a barrier to adopting a different standard PROM or vice versa.

For these reasons, Consumer-Purchaser Alliance generally does not recommend proprietary surveys when similar non-proprietary surveys are available. Unless specifically noted as a proprietary survey, all the PROMs and PRO-PMs in the Selection Guide are publicly available and free to use

[20] Other entities (e.g., health plan, third party, purchaser) can also drive survey administration and data collection, thereby incurring the cost of any license and/or implementation support. We recommend that PRO information always be made available to providers and patients for use in clinical care, in addition to any quality improvement or accountability uses.

[22] See footnote 20 (above)

[23] A special designation of registry that can report clinician quality measures to CMS

Examples of High-Impact PROs Initiatives

PRO information is routinely collected in clinical/health services research, and is increasingly collected and used in clinical practice settings. Internationally, the **Netherlands** uses a routine outcome monitoring (ROM) method to systematically collect PROM/PRO-PM data for over 10 conditions.[24] In the **United Kingdom** (U.K.), PROMs reporting has been mandatory for patients undergoing certain elective surgical since 2009.[25]

In the U.S., the use of PROMs and some PRO-PMs is growing in clinical practice settings. Boston-based **Partners HealthCare** collects PROMs and PRO-PMs across 21 specialties in orthopedics, urology, psychiatry, and cardiac surgery and has stated publicly that "PROMs are essential to real-time clinical care and to how we measure, compare, and improve care as a system".[26] **The University of Rochester Medical Center (URMC)** orthopedic surgery department has collected PROs on physical function, pain interference, and depression during every outpatient clinic visit for the past 3 years – a practice that was expanded throughout 30 URMC departments and divisions. URMC developed a home-grown system called UR VOICE (University of Rochester Validated Outcomes in Clinical Experience), which allows physicians to view patient responses instantly, compare PRO scores to a reference population, and then review the results and individual historical trends with the patient during the face-to-face encounter. URMC is now able to use pre-operative PRO scores to predict the likelihood patients will obtain a clinically meaningful benefit from foot and ankle surgeries. Lastly, of note – the **Intensive Outpatient Care Program (IOCP)**, an initiative aimed at improving outcomes for medically complex patients, uses PROMs to screen for depression and to track each patient's functional health status and ability to engage in improving their health (i.e. patient activation).[27]

Groups, such as clinical registries, that can test measures using existing data sets also have an interest in incorporating PROMs/PRO-PMs into their data sets. Widespread PROs adoption by clinical registries could significantly advance the field of PRO-PMs because they already have robust data collection infrastructure in place. For example, the **American Joint Replacement Registry (AJRR)** collects PROMs information for hip and knee replacement, leading the field by not only publishing hospital-level PRO-PM results but also providing participating clinicians with site-specific patient reports. The AJRR system provides national benchmarks and summary results for each PRO-PM supported. In California, both the state-administered and private plans encourage participation in the American Joint Replacement Registry (AJRR).

Health care purchasers are also promoting the use of PROMs and PRO-PMs. For example, **Blue Cross Blue Shield of Massachusetts (BCBSMA)** began offering financial incentives in 2013 under its Alternative Quality Contract (AQC) to providers who collect and submit PRO survey data on a number of clinical areas including depression, low back pain, and hip/knee surgery – PRO data reporting is no longer voluntary under the AQC. **Blue Shield of California** developed a unique, patient-focused process for evaluating joint replacement surgery that uses PROMs

[25] The U.K reporting program includes PROs for hip and knee replacement, hernia repair, and varicose vein surgery. Results are risk-adjusted and reported as the average change in patient-reported functional health status achieved for every hospital performing these procedures nationwide. See http://www.england.nhs.uk/statistics/statistical-work-areas/proms/

to solicit patients' perspective on the need for and outcomes of joint replacement surgery and to monitor his/her health-related quality-of-life. The results are shared with surgeons, along with aggregate results from all other participating orthopedists, to provide each surgeon with the opportunity to analyze his/her treatment decisions. State purchasers have also been advancing the use of PRO information. For example, the **state of Minnesota** publicly reports results at the medical group level on a standardized set of performance measures, including PROMs.

Condition-specific PROM Recommendations, at-a-glance

The summary table below displays Consumer-Purchaser Alliance's recommended condition-specific measure sets, intended for use as a starting point for each condition when advocating for PROMs/PRO-PMs adoption. To capture all pertinent dimensions of a patient's health-related quality of life, each condition-specific measure set includes both general and disease-specific PROMs and PRO-PMs (see call-out box below). We expect advocates to incorporate other high-value PROMs/PRO-PMs based on specific program needs and as additional PRO-PMs (and other PROMs) become available.

CONDITION	MEASURES	PROM/PRO-PM
Asthma	Optimal Asthma Control	**PRO-PM**
	PHQ-2	**Screening Tool**
	PROMIS-Global or VR-12	**PROM**
Depression	Depression Remission at 12 months *or* Depression Remission at 6 months	**PRO-PM**
	PHQ-2	**Screening Tool**
	PROMIS-Global or VR-12	**PROM**
Coronary Artery Disease	Seattle Angina Questionaire-7	**PROM**
	Rose Dyspnea Scale	**PROM**
	PHQ-2	**Screening Tool**
	PROMIS-Global or VR-12	**PROM**
Heart Failure	Kansas City Cardiomyopathy Questionnaire – Short Version	**PROM**
	PHQ-2	**Screening Tool**
	PROMIS-Global *or* VR-12	**PROM**
Hip Replacement	Hip injury and Osteoarthritis Outcome Score (HOOS) – PS	**PROM**
	PROMIS-Global *or* VR-12	**PROM**
Knee Replacement	Knee injury and Osteoarthritis Outcome Score (KOOS) – PS	**PROM**
	or Average change in functional status following knee replacement surgery	**PRO-PM**
	PROMIS-Global *or* VR-12	**PROM**

Note: We include PHQ-2, a depression screening tool, in 4 of the 6 condition-specific measure sets because depression is systematically underdiagnosed, is a risk factor/common comorbidity for those conditions, and should be routinely assessed in many clinical settings (in addition to primary care). Screening tools are used only to determine whether or not a more comprehensive assessment should be completed – either by the clinician or via another PRO survey.

VALIDATED CROSSWALKS: PROMIS-GLOBAL, VR-12, AND SF-12

To ensure that general health status is assessed, we recommend either the PROMIS-Global or VR-12 measure for each specified condition in the summary recommendation table on page 14 – these two PROMs (and the SF-12) have a validated cross-walk which allows for comparisons of scores across the three surveys. A validated crosswalk provides the raw survey scores that would be obtained on each survey for patients with identical health status, which allows a provider to compare the health status of a patient who completed the VR-12 survey with that of a patient who completed the PROMIS-Global survey. This provides flexibility in administration without undermining any analyses of survey data, by allowing historical trending and analysis even if a switch is made to a different PROM instrument.

The VR-12 (and SF-12) have been used in clinical practice for decades, whereas the PROMIS-Global is part of a suite of innovative PROMIS measures. The Patient-Reported Outcomes Measurement Information System (PROMIS) aims to provide researchers and clinicians with access to efficient, precise, valid, and responsive PROMs that can be used to understand the burden of patients' diseases and the impact of treatment on how patients feel and function in their daily lives. PROMIS leverages developments in technology, as well as advances in the sciences of psychometric, qualitative, cognitive, and health survey research to create new models and modes for collecting PRO information for use in the evaluation of and delivery of medical care. Use of the PROMIS suite of measures is growing in clinical practice, as the suite offers short-form survey options, computer adaptive testing, flexibility in the method of administration, and measures appropriate for children and parent-proxies. PROMIS is a good on-ramp for the future collection and clinical use of PRO-PM data because the suite requires no training, no permission for use, and is appropriate for people with health conditions and for the general population.

GENERAL HEALTH STATUS VS. CONDITION-SPECIFIC PROMS

Condition-specific PROMs are designed to focus narrowly on health status as it relates to a given disease or disability. Condition-specific PROMs are typically better at discriminating among varying levels of condition severity, and are more sensitive for assessing changes in health status/quality of life as it relates to that condition. For example, a cardiac-specific PROM would likely use multiple questions to assess various aspects of chest pain and lung function.

General health status PROMs are designed to assess global health status and/or quality of life using concepts that are relevant to everyone and focus on common indicators of health and well-being. General health status PROMs provide the ability to compare outcomes across different populations, health conditions and methods of treatment – in turn, facilitating health policy and cost-effectiveness analyses. Common concepts include physical functioning, emotional well-being, bodily pain, fatigue, social role limitations due to physical health problems and/or emotional distress, and general perceptions of health.

Selection Guide: Recommended & Other Commonly Used PROMs and PRO-PMs

This guide is comprised of PROMs and PRO-PMs commonly used in clinical practice in the United States that meet the needs of consumers and purchasers and are ready for use in provider reporting and accountability programs. Below, you'll find PROMs/PRO-PMs for general health status and for the following conditions: asthma, cardiovascular disease, depression, hip replacement, and knee replacement. Condition-specific PROMs/PRO-PMs are often paired with assessments of general health status to provide a more thorough assessment of a patient's overall health status. In the tables below, we recommend the highest-value PROMs and PRO-PMs from what is currently available, however, all of the measures and performance measures included below are viable options (unless otherwise noted). Please note that PRO-PMs are available only for three of the five conditions covered in this guide: asthma, depression, and knee replacement.

The tables below are organized beginning with general health status PROMs/PRO-PMs, followed by condition-specific sections in alphabetical order.

General Health Status PROMs: VR-12, PROMIS-Global, SF-12

TITLE	NQF #	PROM OR PRO-PM	DESCRIPTION	COMMENTS
Recommended PROMs				
VR-12	N/A	PROM	12-item survey that assesses physical and mental health	▪ VR-12 is effectively the same survey as the SF-12 (below), with two distinguishing factors: VR-12 is non-proprietary and does not provide condition-specific survey score norms
PROMIS-Global	N/A	PROM	10-item survey that assesses general domains of health and functioning	▪ The NIH funded the development of a suite of PROMIS surveys to advance the field of patient-reported health assessments, one of which is PROMIS-Global ▪ *See call out box on page 13 for more information*
Other Commonly Used PROMs				
SF-36	N/A	PROM	36-item survey that assesses physical and mental health over 8 quality of life domains	▪ This proprietary survey has been in use for over twenty years ▪ Survey score norms for specific conditions can be obtained for many conditions (based on extensive database
SF-12	N/A	PROM	12-item survey that assesses physical and mental health	▪ SF-12 is the short-form version of SF-36 and can be completed by most participants in less than a third of the usual time needed to complete the SF-36 ▪ SF-12 is also a proprietary survey and has the same advantage as SF-36, in that survey score norms can be obtained for many conditions

ASTHMA

Asthma is a chronic condition with many factors contributing to day-to-day experience and management, including genetic, environmental, and psychosocial factors. Generally, goals of asthma treatment are to control or reduce the patient's symptom burden, prevent recurrent asthma attacks, and maintain normal activity levels. PROMs for asthma assess both asthma-specific quality of life and overall management of the condition to identify individuals whose asthma management may be suboptimal. The disease management concepts assessed are wide-ranging, including severity of asthma symptoms, symptom control, behavior and attitude barriers, activity modifications or limitations, and the patient's perception of asthma management. Use of PROMs/PRO-PMs in asthma care is an effective method to identify poor control for individuals, allowing providers to support patients in setting and achieving realistic goals for asthma control.

TITLE	NQF #	PROM OR PRO-PM	DESCRIPTION	COMMENTS
Recommended Measure				
Optimal Asthma Control	NQF #1876	PRO-PM	Composite measure that assesses patient-reported health status and utilization (also patient reported via survey)	■ Mix of patient self-reported functional status and utilization metrics ■ Measure identifies well-controlled patients who are not at risk for exacerbation (fewer than two ED visits or hospitalizations) ■ Allows for choice of one of four PRO surveys (two adult and two child); an evidence-based threshold for control is identified for each survey

DEPRESSION

Depression impacts many types of patients and has the potential to impede management/prognosis of other types of medical conditions. In 2015, an estimated 6.7% (16.1 million) of adults in the U.S. had at least one major depressive episode[28] in the past year.[29] Goals of treatment for major depression include achieving remission, reducing relapse and recurrence, and return to previous levels of occupational and psychosocial function. Under-diagnosis of depression is a persistent concern: depression treatment in the primary care setting has resulted in only about half of depressed adults being treated[30] and only 20% to 40% showing substantial improvement over 12 months.[31] PROMs and PRO-PMs can improve diagnosis and care for patients with depression when used as a screening or monitoring tool.

Note: Of the measures below, all but one are based on the nine-item Patient Health Questionnaire (PHQ-9). PHQ-9 is well developed, has a sound evidence-base, and serves as a multipurpose instrument for screening, diagnosing, monitoring, and measuring the severity of depression. PHQ-9 can be administered frequently and be rapidly scored, which allows providers to easily track improvement or worsening of depression in response to treatment. The PROM's rapid scoring ability also allows providers to adapt his/her treatment decisions quickly to better meet patient needs.[32]

TITLE	NQF #	PROM OR PRO-PM	DESCRIPTION	COMMENTS
Recommended Measure				
Patient Health Questionnaire 2 (PHQ-2)	N/A	Screening Tool	First two questions of PHQ-9	■ This is an ultra-brief screening tool that indicates whether the longer PHQ-9 PROM should be used ■ Used in routine care, this screening tool is particularly valuable for clinicians who do not ordinarily treat depression, to identify underdiagnosed patients and refer them to an appropriate provider
Depression Remission at 12 months	N/A	PROM	Patients (> 18 years) with major depression or dysthymia and a baseline PHQ-9 score > 9 who demonstrate remission at 12 months	■ Measure results quantify patients who are no longer depressed (in remission) at 12 months ■ Longer assessment timeline creates risk of very low follow-up response rates that would impact ability to obtain reliable measure results ■ Included in the AHIP/CMS Core Quality Measure Collaborative ACO/PCMH core measure set

[28] A period of two weeks or longer during which there is either depressed mood or loss of interest or pleasure, and at least four other symptoms that reflect a change in functioning, such as problems with sleep, eating, energy, concentration, and self-image.

[32] The PROM rates the frequency of the symptoms which factors into the scoring severity index, and also screens for the presence and duration of suicide ideation. PHQ-9 scores of 5, 10, 15, and 20 represents mild, moderate, moderately severe and severe depression.

DEPRESSION (CONTINUED)

TITLE	NQF #	PROM OR PRO-PM	DESCRIPTION	COMMENTS
Depression Remission at 6 months	0710	PRO-PM	Patients (> 18 years) with major depression or dysthymia and a baseline PHQ-9 score > 9 who demonstrate remission at six months	■ Same measure as Depression Remission at 12 months, except reassessment occurs at six months ■ More aggressive treatment timeline may create the risk of overuse of medication therapy, however may also create incentives for providers to follow-up with patient more immediately compared to the Depression remission at 12 month measure ■ More appropriate for some accountability programs with a measurement window of 12 months or less.[33] ■ Included in the IHA/PBGH ACO Measure Set
Other Commonly Used Measures[34]				
Depression Response at 12 Months-Progress Towards Remission	1885	PROM	Patients (> 18 years) with major depression or dysthymia and a baseline PHQ-9 score > 9 who demonstrate a 12 months score that is reduced by 50%	■ Measure results quantify improvements made towards reducing depression, which may include patients who are still depressed (i.e., not in remission) ■ Included in the AHIP/CMS CQMC core measure set for ACO/PCMH
Depression Response at Six Months-Progress Towards Remission	1884	PRO-PM	Patients (> 18 years) with major depression or dysthymia and a baseline PHQ-9 score > 9 who demonstrate a six months score that is reduced by 50%	■ Same measure as measure above, except reassessment occurs at six months which is a more aggressive timeline than 12 months and likely to yield a higher follow-up response rate
Depression Utilization of the PHQ-9 PROM	0712	Process Measure	Patients (> 18 years) with major depression or dysthymia who were administered PHQ-9 at least once during the four month measurement period	■ Process measure, requiring providers to document whether the PHQ-9 PROM was administered ■ This measure is often implemented in a set with other measures based on PHQ-9 results, such as the depression remission at 12 and 6 months measures ■ We support using this measure as part of a set of measures including outcomes, but not as a standalone measure
Preventive Care and Screening: Screening for Clinical Depression and Follow-Up Plan	0418	Process Measure	Percentage of patients (> 12 years) screened for depression using a standardized PROM and follow-up plan documented	■ ***We do not recommend use of this measure and have included it in this table only because of its history of inclusion in CMS quality reporting programs*** ■ Process measure, requiring providers to document whether a standardized depression screening tool was administered ■ Measure does not specify assessment instrument, only that the tool be standardized so utility of aggregated data is very limited

[33] A one-year measurement window for a provider contract may not allow for appropriate collection of the 12 month measure, and among commercial programs there may be turnover in enrollment that hurts response rates

[34] Depression Response at 6 months and Depression Response at 12 months are also important measures, and assess improvement (reductions) in depression severity rather than achievement of remission. Both reduction in severity and achievement of remission are important outcomes, and in this toolkit we prioritized the more desirable outcome, remission.

CARDIOVASCULAR DISEASE

Heart disease is the leading cause of death in the United States, accounting for one in every four deaths.[35] When not fatal, it can lead to serious illness, disability, and decreased quality of life. Minimizing the symptom burden of heart disease and preventing further disease progression are central aspects of treatment. Common practice today for evaluating and improving cardiac care focuses primarily on extremely serious clinical outcomes (e.g., mortality, hospital-acquired infections), whereas cardiac PROMs focus on current health status (e.g., physical limitations, symptom frequency, and symptom severity), quality of life, and social limitations. Although most providers initiate discussions about these concepts of health status during routine clinical care, cardiac PROMs allow providers to employ a systematic and standardized approach to assess and track these important aspects of patient health.

TITLE	NQF #	PROM OR PRO-PM	DESCRIPTION	COMMENTS
Recommended PROMs				
SAQ-7	N/A	PROM	7-item shortened version of the Seattle Angina Questionnaire (SAQ, see below), assessing health status specific to coronary artery disease	▪ As the short-form version, this survey assesses 3 of the 5 domains included in the Seattle Angina Questionnaire (SAQ): physical limitation, angina frequency, and quality of life ▪ Addresses one of the critical barriers to routine use of the SAQ, the length of the survey, by reducing the number of survey items from 19 to 7
Kansas City Cardiomyopathy Questionnaire – Short Version	N/A	PROM	12-item shortened version of Kansas City Cardiomyopathy Questionnaire (KCCQ, see below), assessing health status specific to congestive heart failure	▪ As the short form version, this survey assesses 4 of the 7 domains included in the Kansas City Cardiomyopathy Questionnaire (KCCQ): physical limitation, symptom frequency, quality of life, and social function ▪ Addresses one of the critical barriers to routine use of the KCCQ, the length of the survey, by reducing the number of survey items from 23 to 12
Rose Dyspnea Scale	N/A	PROM	4-item survey that assesses difficulty with breathing	▪ Dyspnea is important to monitor as it is associated with impaired quality of life, more frequent re-hospitalization, and reduced survival after heart attack
Other Commonly Used PROMs				
Seattle Angina Questionnaire (SAQ)	N/A	PROM	19-item survey that assesses quality of life for patients with coronary artery disease	▪ Appropriate for patients who have had chest pain (angina), prior heart attacks, angioplasty, stents placed, or bypass surgery ▪ Questions are rolled up into overall score based on 5 domains: angina stability, angina frequency, physical limitation, treatment satisfaction, and quality of life.
Kansas City Cardiomyopathy Questionnaire (KCCQ)	N/A	PROM	23-item survey that assesses quality of life for heart failure patients	▪ Questions are rolled up into overall score based on 7 domains: physical limitation, symptom stability, symptom frequency, symptom burden, self-efficacy, quality of life, and social function
MN Living with Heart Failure Questionnaire	N/A	PROM	21-item survey that assesses quality of life for chronic heart failure patients	▪ Designed to measure the effects of heart failure and treatments for heart failure on an individual's quality of life by assessing symptom burden, functional limitations, and psychological distress ▪ Modest cost for licensing survey (i.e., must pay to use the survey in clinical practice)

HIP AND KNEE REPLACEMENT

7.2 million Americans are currently living with an artificial hip or knee, and this number is expected to grow as the demand for total hip and knee arthroplasty (THA/TKA) surgery increases.[36] THA/TKA procedures are specifically intended to improve function and reduce pain and as such, PRO information is the most meaningful data to use when evaluating treatment success. There are multiple generic and condition-specific PROMs that are validated and used to evaluate patient-reported symptoms, pain, and functional status for THA/TKA patients. However, although the HOOS and KOOS PROMs are gaining significant traction in use in clinical practice, there is no PRO-PM available for use.

TITLE	NQF #	PROM OR PRO-PM	DESCRIPTION	COMMENTS
Recommended PROMs				
Knee injury and Osteoarthritis Outcome Score (KOOS) Jr.	N/A	PROM	7-items survey that assesses pain, stiffness, and physical functioning related to knee health	■ Recently developed as the short-form version of KOOS (see below) by a premier research institution (Hospital for Special Surgery) ■ Assesses aspects of pain with activities and degree of difficulty with physical functioning ■ Included in the CMS Comprehensive Joint Replacement (CJR) program's voluntary PROM option and American w Joint Replacement Registry ■ KOOS developer also created another short-form, KOOS-PS, but it is used less frequently in accountability programs than KOOS Jr.
Hip injury and Osteoarthritis Outcome Score (HOOS) Jr.	N/A	PROM	6-item survey that assesses pain and physical functioning associated with hip health	■ Recently developed as the short-form version of HOOS (see below) by a premier research institution (Hospital for Special Surgery) ■ Assesses pain with activities and degree of difficulty with physical functioning ■ Included in the CMS Comprehensive Joint Replacement (CJR) program's voluntary PROM option and American Joint Replacement Registry ■ HOOS developer also created another short-form, HOOS-PS, but it is used less frequently in accountability programs than HOOS Jr.
Average change in functional status following knee replacement surgery	2653	PRO-PM	Average change from pre-operative to post-operative functional status (nine to fifteen months)	■ Measured using the Oxford Knee Score survey, which has more acceptance by providers internationally ■ Developed by Minnesota Community Measurement

HIP AND KNEE REPLACEMENT (CONTINUED)

TITLE	NQF #	PROM OR PRO-PM	DESCRIPTION	COMMENTS
Other Commonly Used Measures				
Knee injury and Osteoarthritis Outcome Score (KOOS)	N/A	PROM	42-item survey that generates five (separately scored) subscales: pain, other symptoms, activities of daily living, sports and recreation function, and knee-related quality of life	■ Survey is intended to be used over short- and long-term time intervals, to assess changes from week to week induced by treatment or over years following a knee injury or post-traumatic osteoarthritic ■ Survey includes two different subscales of physical functioning which enhances the instrument's validity for patients with a wide range of current and expected physical activity levels ■ This non-proprietary survey is used widely in clinical trials, research studies, registries, and clinical practice ■ Survey is included in PRO voluntary option for CMMI's Comprehensive Joint Replacement Care, BCBS MA Alternative Quality Contract, and multiple US registries
Hip injury and Osteoarthritis Outcome Score (HOOS)	N/A	PROM	40-item survey that generates five separate subscales: pain, other symptoms, activity of daily living, sport and recreation function, and hip-related quality of life	■ Similar to the KOOS, this survey is also applicable for younger and more active people as it uses two different subscales of physical functioning ■ This non-proprietary survey is used widely tested in clinical trials, research studies, registries, and clinical practice ■ Survey is included in PRO voluntary option for CMMI's Comprehensive Joint Replacement Care, BCBS MA Alternative Quality Contract, and multiple US registries

Endnotes

[1] Isaac, T., Zaslavsky, A. M., Cleary, P. D., & Landon, B. E. (2010). The Relationship between Patients Perception of Care and Measures of Hospital Quality and Safety. *Health Services Research*,45(4), 1024-1040. doi:10.1111/j.1475-6773.2010.01122.

[3] Institute of Medicine (US) Committee on Quality of Health Care in America. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington (DC): National Academies Press (US); 2001. Available from: https://www.ncbi.nlm.nih.gov/books/NBK222274/doi: 10.17226/10027

[5] PCORI: Our Story. (2017, June 05). Retrieved from https://www.pcori.org/about-us/our-story

[6] Intro to PROMIS. (n.d.). Retrieved from http://www.healthmeasures.net/explore-measurement-systems/promis/intro-to-promis

[7] *CMS Quality Measure Development Plan: Supporting the Transition to the Merit-based Incentive Payment System (MIPS) and Alternative Payment Models (APMs)*. (2016, May 2). Retrieved https://www.cms.gov/Medicare/Quality-Initiatives-Patient-Assessment-Instruments/Value-Based-Programs/MACRA-MIPS-and-APMs/Final-MDP.pdf

[8] Nilsson, E., Orwelius, L., & Kristenson, M. (2015). Patient-reported outcomes in the Swedish National Quality Registers. *Journal of Internal Medicine*, 279(2), 141-153. doi:10.1111/joim.12409

[11] Health Care Payment Learning & Action Network. *Accelerating and Aligning Clinical Episode Payment Models*. August 1, 2016.

[12] Rotenstein, L. S., Huckman, R. S., & Wagle, N. W. (2017). Making Patients and Doctors Happier — The Potential of Patient-Reported Outcomes. *New England Journal of Medicine*,377(14), 1309-1312. doi:10.1056/nejmp1707537

[14] Wagle, N. W. (2017, October 12). Implementing Patient-Reported Outcome Measures. Retrieved from http://catalyst.nejm.org/implementing-proms-patient-reported-outcome-measures/

[15] Kalantar, J. S., & Talley, N. J. (1999). The Effects of Lottery Incentive and Length of Questionnaire on Health Survey Response Rates. *Journal of Clinical Epidemiology*,52(11), 1117-1122. doi:10.1016/s0895-4356(99)00051-7

[16] Kreuter, M. W. (2000). How Does Physician Advice Influence Patient Behavior?: Evidence for a Priming Effect. *Archives of Family Medicine*,9(5), 426-433. doi:10.1001/archfami.9.5.426

[17] Rubak, S., Sandbæk, A., Lauritzen, T., & Christensen, B. (2005, April 01). Motivational interviewing: A systematic review and meta-analysis. Retrieved from https://bjgp.org/content/55/513/305/tab-pdf

[18] Boulware, E., Flynn, S., Ameling, J., Hill-Briggs, F., Wolff, J., Bone, L., . . . Ramamurthi, H. (2013). Facilitators and barriers to hypertension self-management in urban African Americans: Perspectives of patients and family members. *Patient Preference and Adherence*,741. doi:10.2147/ppa.s46517

[19] Chenok, K. E., Teleki, S., Soohoo, N. F., Iii, J. H., & Bozic, K. J. (2015). Collecting Patient Reported Outcomes: Lessons from the California Joint Replacement Registry. *EGEMs (Generating Evidence & Methods to Improve Patient Outcomes)*,3(1), 20. doi:10.13063/2327-9214.1196

[21] Snyder, C. F., Aaronson, N. K., Choucair, A. K., Elliott, T. E., Greenhalgh, J., Halyard, M. Y., . . . Santana, M. (2011). Implementing patient-reported outcomes assessment in clinical practice: A review of the options and considerations. *Quality of Life Research*,21(8), 1305-1314. doi:10.1007/s11136-011-0054-x

[24] van der Wees, Philip. (2013). *Patient-reported outcomes in the Netherlands: Routine use in clinical practice and performance measurement* [PowerPoint slides]. Retrieved from: https://www.kingsfund.org.uk/sites/default/files/media/phil-van-der-wees-proms-netherlands-dec13.pdf

[26] Wagle, N. W. (2017, October 12). Implementing Patient-Reported Outcome Measures. Retrieved from http://catalyst.nejm.org/implementing-proms-patient-reported-outcome-measures/

[27] Stremekis, K., Connors, C., & Hoo, E. (2017, September 26). Intensive Outpatient Care Program: A Care Model for the Medically Complex Piloted by Employers. Retrieved from https://www.commonwealthfund.org/publications/case-study/2017/sep/intensive-outpatient-care-program-care-model-medically-complex

[29] Major Depression. (2017, November). Retrieved from https://www.nimh.nih.gov/health/statistics/prevalence/major-depression-among-adults.shtml

[30] Kessler RC, Chiu WT, Demler O, Merikangas KR, Walters EE. Prevalence, Severity, and Comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. Arch Gen Psychiatry. 2005 Jun; 62(6):617-627

[31] Unutzer J, Katon W, Callahan CM, William JW Jr, Hunkeler E, Harpole L, Hoffing M, Della Penna RD, Noel PH, Lin EH, Arean PA.... Langston C. Collaborative Care Management of Late-Life Depression in the Primary Care Setting: A Randomized Controlled Trial. JAMA. 2002 Dec 11; 288(22):2836-45

[35] Heart Disease Facts & Statistics. (2017, November 28). Retrieved from https://www.cdc.gov/heartdisease/facts.htm

[36] Maradit Kremers, H., Larson, D. R., Crowson, C. S., Kremers, W. K., Washington, R. E., Steiner, C. A., ... Berry, D. J. (2015). Prevalence of Total Hip and Knee Replacement in the United States. *The Journal of Bone and Joint Surgery*. American Volume, 97(17), 1386-1397. http://doi.org/10.2106/JBJS.N.01141