Consumer Assessment of Healthcare Providers and Systems
(CAHPS®)
2024 Research Meeting Summary

Patient-Reported Experience and Outcome Measures (PREMs and PROMs) in Research and Clinical Practice

November 2024

Agency for Healthcare
Research and Quality

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Introduction

The U.S. Agency for Healthcare Research and Quality (AHRQ) hosted a free virtual research meeting on September 17, 2024, to focus on the use of patient-reported experience and outcome measures (PREMs and PROMs). The meeting was designed to address the following questions:

- What are the differences between PREMs and PROMs?
- How are PREMs and PROMs interconnected?
- How can PREMs and PROMs best be used to improve quality and promote value-based healthcare?
- In what ways can PREMs and PROMs be used to better understand the patient's voice?
- What are future directions for PREMs and PROMs research and use in clinical practice?

Approximately 450 CAHPS survey users, researchers, healthcare organization leaders, patient advocates, policymakers, and Federal partners attended.

Key Themes

- The use of patient-reported measures—such as PREMs and PROMs—is integral to improving healthcare quality and safety.
- PREMs are measures that help us to understand and improve patients' experiences.
- PROMs are measures that help us to understand and improve patients' outcomes.
- PREMs and PROMs are often used independently, yet their data are complementary. Analyzing data from PREMs and PROMs together can yield a more holistic assessment of patients' entire healthcare experiences.
- Using PREMs and PROMs in a meaningful way necessitates buy-in from both providers and patients.
- PREMs and PROMs ultimately should be about what matters most to the patient.
- Although much progress has been made toward the collection of PREMs and PROMs data, many challenges still exist.
- Clinicians need to promote the value of patient-reported measures and how they are used so patients can meaningfully engage in their own care.
- PREMs and PROMs are effective at guiding improvement and assessing value in healthcare because they measure actual patient experiences and outcomes rather than processes.
- Utilizing patient-reported measures is essential for shared decision-making between clinicians and their patients, which in turn enables patients to clearly understand their conditions and feasible treatment options.
- Incentivizing the use of PROMs—as is already done with many PREMs—via ties to reimbursement will help to expand their utilization.

Welcome and Overview

Joann Sorra, Ph.D., Vice President, Westat
Laura L. Sessums, J.D., M.D., Chief Medical Officer, Office of the Director, Agency for Healthcare Research and Quality
Karen Chaves, M.H.S., Director, Division of Quality Measurement and Improvement, Center for Quality Improvement and Patient Safety (CQuIPS), Agency for Healthcare Research and Quality


Joann Sorra


Laura Sessums


Karen Chaves

The Agency for Healthcare Research and Quality (AHRQ) is a research agency that aims to enhance patients' lives and support healthcare systems and organizations in the delivery of high quality, safe, and valuable care. Toward this end, AHRQ produces data tools, research evidence, and strategies that support improved healthcare delivery.

Among the tools developed by AHRQ are the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) surveys. They are widely recognized patient-reported experience measures (PREMs) that serve as critical tools for organizations that aim to assess the patient-centeredness of care and identify areas for improvement. PREMs may be used with other means of assessing patient experience—such as focus groups, observation, and patient and family advisory councils—to achieve a more comprehensive understanding of the state of patient experience.

PREMs results can also be used to complement patient-reported outcome measures (PROMs), which are patients' self-reports about their health, including physical, social, and mental health. Like PREMs, PROMs data are collected using multiple modes.

There are currently challenges to collecting PREMs and PROMs data, and challenges to making patients aware of how their data are used to foster improvement. However, PREMs and PROMs—used together—can provide unique and synergistic information about quality of care and how patient experience is related to patient outcomes.

Keynote Address

Eugene Nelson

How Patient Experience and Patient-Reported Outcome Measures Are Interconnected

Eugene Nelson, D.Sc., M.P.H., Professor of the Dartmouth Institute and of Community and Family Medicine Emeritus

Using PREMs and PROMs significantly improves healthcare experience, outcomes, equity, quality, value, and science by amplifying the patient's voice.

Three models illustrate the interconnectedness between PREMs and PROMs. These models demonstrate how PREMs and PROMs can be integrated to enhance healthcare quality and patient engagement:

1. **Donabedian Model:** This model is the most well-known for improving quality. It highlights that healthcare quality is a function of structure, process, and outcomes. PREMs are used to measure the process of receiving care, and PROMs are used to measure outcomes based on patient reports and findings.
2. **Deming Model:** The Deming Model which focuses on continuous improvement, has also been applied in the healthcare context. PREMs provide insights into healthcare processes through the eyes of the patient, while PROMs assess the outcomes of care through the eyes of the patient.
3. **Value Compass Model:** This model describes the patient's journey through the healthcare process. PREMs and PROMs can be used to measure goodness of care and experience, as well as health outcomes related to physical, mental, and social functioning and overall quality of life.

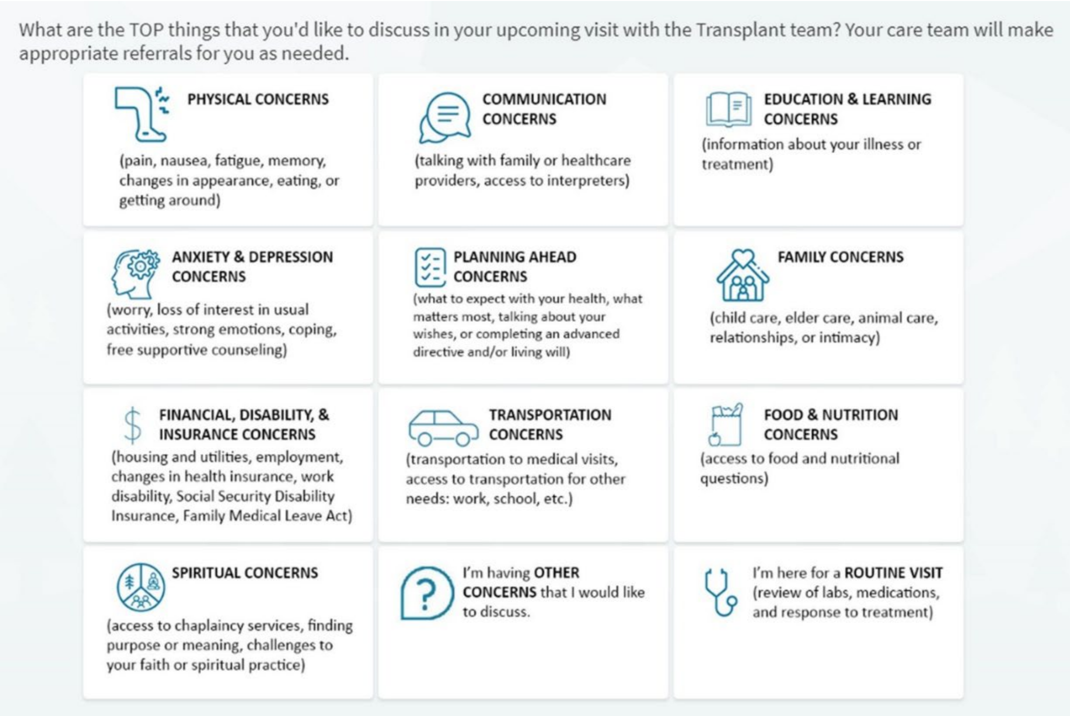
Several case studies illustrate the practical application of PREMs and PROMs:

1. **Dartmouth Spine Center:** A spine program that brought together all the specialists and services that spine patients need in one place has benefited from the use of patient-generated data. The program process entailed patients completing health status surveys prior to seeing their clinicians. The surveys consisted of PROMs that tracked changes in physical, mental, and social functioning over time. Then, patients' ratings of their treatment results were compared with their expectations of good results.

   Dr. Jim Weinstein, who helped to launch the spine program at Dartmouth, conducted a six-year randomized controlled trial comparing surgical and non-surgical treatments for common back problems. The study found that although both groups showed symptom improvement, the surgical group had better outcomes after two years. Also, satisfaction rates were higher in the surgical group (78%) versus the non-surgical group (59%). The medical costs for the surgical group were higher, so better results came at greater expense. However, the cost estimate per quality-adjusted life must also be considered. The data from the study were later used for personalized, predictive medicine—that is, making patient-specific predictions based on evidence.

2. **The Swedish Rheumatology Quality Register Approach:** In 2000, Dr. Staffan Lindblad, inspired by the Dartmouth Spine Center, implemented a similar system in Sweden for rheumatoid arthritis (RA) patients. Dr. Lindblad organized and led an RA registry that included most of the adult patients in Sweden. This system included patient self-management modules to report symptoms and a clinician module that showed trends over time in patient-reported outcomes. Dramatic and consistent improvement was achieved with patients who actively worked with their clinicians and submitted patient-reported information. This improvement has continued since 2004.

3. **Dartmouth Cancer Center:** Focusing on transplant and cellular therapy (TCT), this program uses PREMs and PROMs to identify and address patient goals and improve symptom management. PREMs (collected via the CAHPS Clinician & Group Survey) and PROMs are collected up to one week prior to a visit via the electronic health record patient portal or a tablet at check-in. The overall participation in this program has been 80%. In addition to PROMs and PREMs, agenda-setting questions (see figure below) ask patients to define goals and state values to better inform the care team. The workflow integrates patient-generated data with clinical information to enhance care quality and patient engagement. The use of PREMs and PROMs has resulted in increased patient perceptions of shared decision-making, discussing what matters most, and creating a care plan that can easily be adhered to at home.



What are the TOP things that you'd like to discuss in your upcoming visit with the Transplant team? Your care team will make appropriate referrals for you as needed.

PHYSICAL CONCERNS (pain, nausea, fatigue, memory, changes in appearance, eating, or getting around)	**COMMUNICATION CONCERNS** (talking with family or healthcare providers, access to interpreters)	**EDUCATION & LEARNING CONCERNS** (information about your illness or treatment)
ANXIETY & DEPRESSION CONCERNS (worry, loss of interest in usual activities, strong emotions, coping, free supportive counseling)	**PLANNING AHEAD CONCERNS** (what to expect with your health, what matters most, talking about your wishes, or completing an advanced directive and/or living will)	**FAMILY CONCERNS** (child care, elder care, animal care, relationships, or intimacy)
FINANCIAL, DISABILITY, & INSURANCE CONCERNS (housing and utilities, employment, changes in health insurance, work disability, Social Security Disability Insurance, Family Medical Leave Act)	**TRANSPORTATION CONCERNS** (transportation to medical visits, access to transportation for other needs: work, school, etc.)	**FOOD & NUTRITION CONCERNS** (access to food and nutritional questions)
SPIRITUAL CONCERNS (access to chaplaincy services, finding purpose or meaning, challenges to your faith or spiritual practice)	I'm having **OTHER CONCERNS** that I would like to discuss.	I'm here for a **ROUTINE VISIT** (review of labs, medications, and response to treatment)

Agenda Setting Questions

4. **Rural Academic Health System:** Brant Oliver, Ph.D., Associate Professor at The Dartmouth Institute for Health Policy and Clinical Practice, uses PREMs to improve care experiences in an eight-hospital rural academic health system focusing on inpatient care. The system links mission and strategic plan drivers with Center for Medicare & Medicaid Services (CMS) star ratings to identify areas for improvement and achieve notable performance gains. Launched in 2023, the program broke the national benchmark of 75th percentile performance twice in the past three months and for the first time since 2021.

Although the interplay of PREMs and PROMs is off to a good start, there is still a long way to go. Healthcare providers are in a helping profession, and as such their aim is to help people stay healthy, heal, and live their best lives. The opportunity exists to mainstream the uptake and use of PREMs and PROMs for patients, the population, and for research.

Part I: PREMs and PROMs in Research

Ashley Wilder Smith

Capturing Patient-Reported Data Using PREMs and PROMs: Measurement, Research, and Care Delivery

Ashley Wilder Smith, Ph.D., M.P.H., Chief, Outcomes Research Branch, Healthcare Delivery Research Program, National Cancer Institute

In the past, patient health status was generally reported by clinicians. However, obtaining clear and standard input from patients to gain a full understanding of their perceptions of their health and healthcare is critical. One way to achieve this is by linking and integrating PREMs and PROMs to enhance patient-centered research and care.

The National Institutes of Health (NIH) emphasizes the importance of understanding care experiences and outcomes. As a result, NIH focuses on capturing patient information through rigorous methods to identify their perspectives in valid and reliable ways. This includes supporting projects that enhance the understanding and use of PREMs and PROMs. As such, the NIH collaborates with a host of partners, including AHRQ, CMS, the Food and Drug Administration (FDA), the Veterans Health Administration (VA), and many others in both the public and private sectors.

NIH Focus on Patient-Reported Health Data

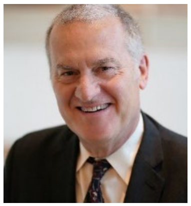
- Support measure development and methods to improve interpretation
- Use in observational studies and clinical trials to complement, extend, and interpret clinical and biologic data
- Healthcare delivery research
    - Research to examine real-world evidence on care and health outcomes
    - Use of implementation science: adoption, adaption, scaling, sustainability
- Support reporting of health and care quality: registry reporting, quality reporting, value-based payment
- Collaborate with partners in the public and private sectors

Two specific data resources that focus on cancer-related PREMs and PROMs are the SEER-MHOS (Surveillance Epidemiology and End Results combined with the Medicare Health Outcome Survey) which captures cancer registry data from the Medicare Health Outcomes Survey, and SEER-CAHPS, which links cancer registry data with responses from the Medicare version of the CAHPS Health Plan Survey. These resources use existing CMS patient-reported data for research purposes, providing comprehensive data sets to investigators.

Future directions for linking PREMs and PROMs in research include:

- Developing evidence to support the interpretation of PREMs and PROMs in clinical care settings,
- Supporting or conducting studies that provide meaningful interpretation of patient-reported measures,
- Presenting PREMs and PROMs data side-by-side to determine relationships between health outcomes and care experiences, and
- Extending and interpreting clinical outcomes and biologic data.

PROMs and PREMs in Research


David Cella

David Cella, Ph.D., Professor and Founding Chair, Department of Medical Social Sciences, Feinberg School of Medicine, Northwestern University

Various similarities and differences exist between PREMs and PROMs. Both are patient-reported measures, but they serve different purposes. PREMs evaluate healthcare delivery, while PROMs assess patient care outcomes. PREMs are more widely used in clinical practice due to mandates. Yet a recent study showed that patients overwhelmingly prefer PROMs to PREMs, even though the use of PROMs is less common because they are underutilized in clinical practice. However, the mandating of PROMs is trending and could result in greater and more consistent use, ultimately benefiting patients.

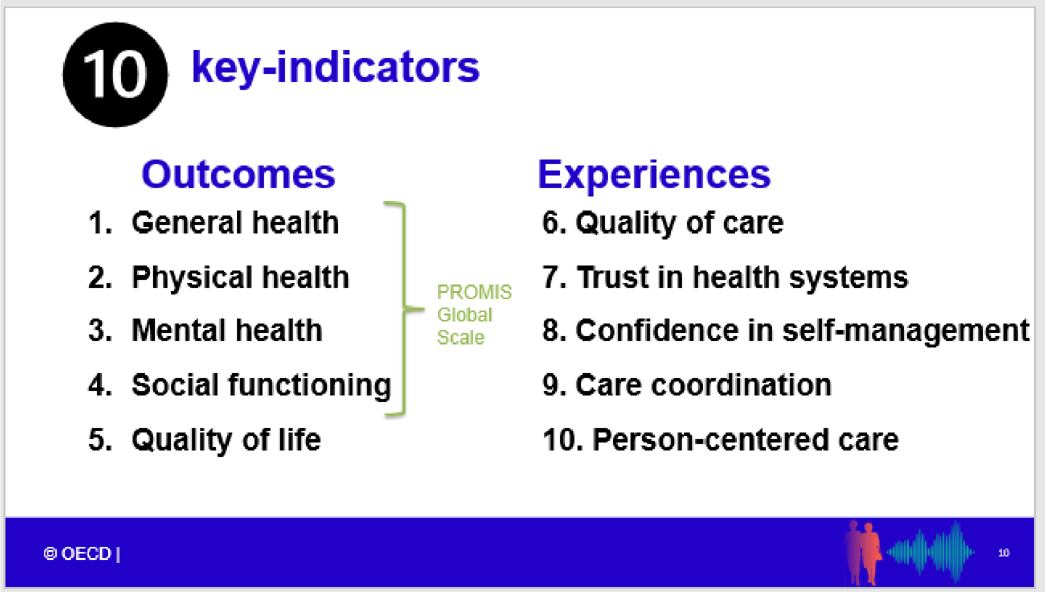
There are several challenges to implementing both types of measures in research and clinical practice. Key challenges include:

- Knowing what to ask and how to interpret it
- Engaging both patients and clinicians
- Integrating PROMs into clinical workflows
- Integrating both measures with information technology

To these points, clinicians often question the value of structured questionnaires, often asking, “Why should I do this? I already talk to my patients and know how they’re doing.” Furthermore, perceptions exist that PROMs slow down clinical workflows despite evidence that they can improve efficiency when they are successfully integrated into workflows. Low response rates for both PROMs and PREMs are also a challenge.

To facilitate greater use of PROMs, a comprehensive Patient-Reported Outcomes Measurement Information System (PROMIS) was developed over the course of 20 years. The PROMIS framework covers physical, mental, and social health domains. A product of data contributions from more than 200,000 people, PROMIS consists of item banks (sets of questions that are calibrated to work together) with more than 2,500 questions for adults and more than 800 for children covering universal health concepts applicable to various diseases. PROMIS was initially an NIH effort to standardize patient-reported outcomes for clinical research; however, it has expanded to include clinical practice and quality measurement. Drawing the PROMIS measures from item banks allows for efficient and customized assessments. The PROMIS Global 10 tool is widely used, as it assesses overall physical and mental health.

An instrumental example is the Patient-Reported Indicator Surveys (PaRIS), an initiative of the Organisation for Economic Co-operation and Development (OECD). OECD serves as a knowledge hub for data, analysis, and best practices in public policy. PaRIS aims to assess healthcare outcomes and patient experiences internationally, focusing on health systems' performance in delivering primary care services for patients with chronic conditions. Part of this includes creating benchmarks for PROMs and PREMs. PaRIS is surveying across 19 countries and more than 1,500 practices, measuring 10 key indicators (below). Results are expected to be released on February 20, 2025.



10 key-indicators

Outcomes

1. General health
2. Physical health
3. Mental health
4. Social functioning
5. Quality of life

PROMIS Global Scale

Experiences

6. Quality of care
7. Trust in health systems
8. Confidence in self-management
9. Care coordination
10. Person-centered care

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10

PaRIS Key Indicators

Part II: The Use of PREMs and PROMs in Value-Based Healthcare

Including PREMs and PROMs in Value-Based Payment Models

Dana Gelb Safran

Dana Gelb Safran, D.Sc., President and CEO, National Quality Forum

Modern value-based payment models differ from 1990s capitation models by combining accountability for a total cost of care with quality outcomes and patient experience. As a result, the system for delivering and transforming healthcare has changed. Quality measures, including patient-reported measures, provide an important counterbalance to the cost accountability of value-based payment models, ensuring that efforts to manage the total cost of care do not result in the underuse of appropriate services or in poor patient care experiences.

Patient-reported measures are crucial for driving optimal patient outcomes. Due to increased accountability for patient experience, including public reporting of patient experience scores and, in some instances, financial incentives linked to these scores, health systems and practices across the country are devoting significant resources to optimizing patient experience. As a result, the wide use of PREMs, such as the CAHPS suite of surveys, has transformed healthcare. Still, there are widespread challenges and concerns about the current generation of PREMs, as well as a desire to see both the content and the technologies for administering surveys evolve. Low response rates, survey length, and burden are among the leading concerns. Leveraging technology for survey administration could enable greater depth while achieving more brevity. A key challenge with including PREMs in value-based healthcare is collecting specific information about a wide range of topics without overburdening patients with too many questions. Modern approaches, such as natural language processing for narrative responses and mobile-friendly dynamic designs, may be key to achieving this balance.

In addition to PREMs, PROMs are critical to include for value-based payment, as they measure improvements in patients' functional status and well-being. Yet PROMs are rarely used in value-based payment models today, and as a result, scaled adoption and use of PROMs in clinical practice is the exception, not the norm. As payers incorporate PROMs into their value-based payment models, their use will likely increase. Ultimately, those accountable for the total cost of care will appreciate that PROMs can provide evidence regarding which treatments are most effective and for whom – yielding success at managing total cost of care while producing favorable patient outcomes.

Ultimately, the heart of the matter is, "Have we helped patients to feel better and function better?" Both PREMs and PROMs are central to value-based payment models. However, significant advances are needed for them to realize their full potential.

Challenges and Opportunities for PREMs and PROMs

Gregg Meyer

Gregg Meyer, M.D., M.Sc., Professor of Medicine, Massachusetts General Hospital and Harvard Medical School, and Professor of Health Policy and Management, Harvard Chan School of Public Health

Many challenges exist with the use of PREMs and PROMs in value-based programs. For PROMs, in particular, there is a need for standardization. While CAHPS surveys have become standardized and integrated into payment systems, PROMs lack this level of standardization to compare data. This makes it difficult to benchmark performance across organizations. Thus, addressing certain challenges is necessary to fully realize the potential of PREMs and PROMs in value-based payment models.

Healthcare has changed since the 1990s, evolving from a capitated care system to value-based care. Value-based care entails not only accountability for a total cost of care but also accountability for quality and safety. A significant advancement that helps with that accountability is the increased use of electronic health records (EHRs). However, EHRs are primarily designed around payment functions. Thus, substantial updates to EHR systems are necessary to facilitate the collection of patient-reported outcomes. This will involve addressing several challenges—such as the complexity of updating EHRs, response biases, and the very practical issue of cost.

Considering the challenges involved, the use of PROMs has come at a slower pace than expected. Resources are limited, and engaging both clinicians and patients to use them has been difficult. Integrating PROMs into existing data collection processes could reduce costs—much like how the costs of collecting PREMs have decreased over time due to standardization and financial incentives. In contrast to PREMs, the lack of a competitive vendor marketplace for PROMs has hindered widespread adoption. So, there is a significant disconnect between wanting to have metrics that matter and pertain to patients in ways they understand versus achieving breadth in the information collected.

Still, there is reason to be optimistic for the future, with many feasible opportunities for improvement that pertain to both PREMs and PROMs. First, health services researchers must clearly define the use of these metrics for accountability and improvement. Additionally, they must find ways to reduce the respondent burden of too many surveys. They also must learn how to present data to providers effectively in a way that will motivate better performance.

Additionally, they need to move the adoption of PREMs and PROMs forward by leveraging the marketplace (in terms of insurance companies and delivery systems) to facilitate public reporting of healthcare performance for both experience and outcomes. This may necessitate some education about why these measures are important. The whole movement of "what matters to me" may signal the beginning of this. But there is much more to do.

CMS Innovation Center's Patient-Reported Measurement Strategy

Susannah Bernheim

Susannah Bernheim, M.H.A., Chief Quality Officer/Acting Chief Medical Officer, Center for Medicare and Medicaid Innovation

The CMS Innovation Center's strategy focuses on the use of patient-reported measures in payment and service delivery models. Launched in 2010, the CMS Innovation Center tests new models within Medicare and Medicaid to reduce costs and improve healthcare quality. Successful models can be expanded to all of Medicare. This fundamentally means that testing of measures is crucial, particularly for incentivizing improvements and assessing model progress.

The Innovation Center's models are diverse, targeting specific conditions (such as end-stage renal disease or cancer), healthcare providers, and statewide initiatives such as the Maryland Total Cost of Care model. According to a 2022 report to Congress, the Innovation Center has impacted more than 41 million beneficiaries (including patients and caregivers) and more than 314,000 providers.

Reflecting on its first decade, the Innovation Center refreshed its vision for the next 10 years, emphasizing equitable, high-quality, affordable, person-centered care. Five strategic objectives guide this vision: driving accountable care, advancing health equity, supporting innovation, addressing affordability, and partnering for system transformation. Success is defined by the extent to which healthcare is based on value to the patient instead of volume of services provided, and delivering person-centered care that meets people where they are. The strategy refresh ultimately drives patient-reported measurement activities.

To support the strategy, the Innovation Center aims to incorporate patient-reported measures into new payment and service delivery models. These measures align care with patients' goals, values, and preferences. Part of the goal is set to increase the percentage of models using at least two patient-reported measures. Many might consider this as focusing only on PROMs; however, a broader strategy incorporates both PREMs and PROMs. Together, these patient-reported measures serve dual purposes: incentivizing accountability and improvement and evaluating the overall impact on beneficiaries. This approach is intended to drive care transformation and expand successful models.

The Innovation Center's measurement strategy is guided by three principles:

1. Aligning the primary goals of the model. This drives the focus to design new models on the features of existing models that are most likely to foster improvement.
2. Advancing person-centered care measurement. This focuses on the quality measures used for improvement and accountability and elevates the use of these measures.
3. Focusing on model evaluation. Rigorous evaluation enables further understanding of model impact, and generates evidence needed for model refinement and expansion.

Various tools and measures are tailored to individual models—such as assessing symptoms, self-management skills, functional outcomes, and patient experience. Examples include:

- The Kidney Care Choices model uses tools to assess patient activation for managing end-stage renal disease.

- The Making Care Primary model captures patient voices to transform primary care practices.
- The Guiding an Improved Dementia Experience model focuses on supporting caregivers and assessing their experiences.
- The Enhancing Oncology Model focuses on implementing tools (with flexibility for tool choice) to collect patient-reported symptom information electronically.

Implementing patient-reported measures isn't easy for either providers or patients. Some sophisticated technical solutions exist, but those are not universal. Addressing these challenges includes being selective with what measures are chosen, aligning them with model goals, and allowing time for capacity building. Efforts are also underway to align measures across CMS and other payers, and to ensure they advance health equity by testing with diverse populations and offering them in multiple languages.

Ultimately, the goal is to make these measures meaningful for clinical care, rather than just checking boxes. This involves careful selection, support for implementation, and tracking improvements to ensure a positive impact on providers and patients.

Patient-Centered Outcome Measures in Value-Based Healthcare


Elizabeth Teisberg

Elizabeth Teisberg, Ph.D., Executive Director, Value Institute for Health & Care, and Professor, Dell Medical School, The University of Texas at Austin

Patient-centered outcomes are crucial in healthcare, as they aim to improve quality of life and dignity in death. It is essential to measure what matters to patients and families. This is crucial for driving learning and improvement, not just changing payment structures.

High-value care focuses on helping those who need it (including those who are not currently receiving care) and ensures equity. Outcome measures are necessary rather than just process or hospitality measures. Outcome measures are essential for value-based payments to be effective.

Process measures alone do not necessarily save lives. The point is to measure what matters instead of the process as science and knowledge evolve. For instance, consider families with medically complex children. A process measure might be to evaluate the need for a new wheelchair every five years, whereas an outcome measure would evaluate whether the wheelchair increases independence and comfort. Contrary to what some might think, measuring outcomes does not entail extra work. Rather, it's simply meaningful work, and that is what improves patient outcomes. An additional consideration is that when healthcare providers can view their work as meaningful, it helps to prevent burnout.

So much attention is focused on acute care, which in the past has been the exclusive focus of the healthcare system. But most healthcare today is for chronic, long-term, lifelong conditions. Usually, with chronic illness, clinicians measure time one, time two, and so on. Focusing on continuous outcomes, rather than just initial or final states, provides a more accurate picture of patient well-being. Simple measures such as nausea, ability to work, or sleep quality can be very telling. It is important to remember such measures and respond to the patient.

Patients need to know that what is being fed into the system is useful, and they ought to be able to feel it in their own care. One challenge is that even when the response rate for patient-reported measures is high, only a small percentage of physicians open them because they view these measures as more of a research tool. Healthcare organizations also need to use these measures in clinical care. It’s not that hospitality measures or safety measures aren’t important, as they are. But respect, safety, compassion, and politeness should be the floor—not the stretch goal.

An example framework for achieving this entails listening to patient discussions to focus on capability, comfort, and calm. For instance, an example with breast cancer patients revealed that cognitive impairment such as “chemo brain” is of significant concern to them. Yet, it is not being measured or addressed in clinical care. Such instances underscore the need for outcome measures that reflecting patient experiences and needs. Furthermore, cancer patients experience an emotional challenge when informing loved ones of their diagnosis. Relationship-centered care can address this by providing support on communicating such news.

These are simple measures of capability, comfort, and calm that can drive care improvement. However, if a person is not improving, providers should not ask patients what is wrong with them but how care can be accommodated for their needs to succeed. Changing care processes, rather than blaming patients, can close gaps in care and promote equitable outcomes.

Part III: PREMs and PROMs in Clinical Practice

Predicting Surgical Outcomes: The Next Frontier of PROMs


Eric Makhni

Eric Makhni, M.D., M.B.A., Director, Quality and Informatics, Orthopaedic Service Line, Henry Ford Health System

Consider two patients facing knee replacement surgery: a young woman who is an avid tennis player but has knee pain compared to an older woman who is sedentary and doesn’t walk much due to pain. Which patient would have a better outcome after knee replacement? One might think that both should have the same outcome because they both have the same diagnosis. However, it is more likely that the older person who has more pain will have better-reported outcomes. This is because patients who start from a worse functional and pain perspective often have more modest expectations than those who are highly active, and often have better perceived outcomes after surgery. The tennis player has greater expectations for recovery to become active again, while the sedentary person just wants to be able to walk. Additionally, the person with more pain will have a bigger drop in their pain score. And the active person with less pain may experience more pain after having surgery.

This counterintuitive result highlights the importance of managing patients’ expectations based on their starting point. This assertion is supported by research, as the data show patients who start with worse conditions experience more substantial improvements. This reinforces the predictive value of PROMs across various orthopedic specialties.

With respect to PROMs, a patient's post-operative condition can be assessed using specific metrics, including:

- MCID (Minimum Clinically Important Difference): The smallest change in a treatment outcome a patient would identify as important.
- SCB (Substantial Clinical Benefit): A significant improvement in a patient's condition.
- PASS (Patient Acceptable Symptomatic State): Whether a patient is satisfied with the symptoms post-treatment.

These metrics help anchor score changes to patient perceptions of improvement. This can be done through statistical analysis and patient feedback.

The incorporation of PROMs is essential to shared decision-making. Clinicians should consider PROMs and other factors such as patient history and imaging results. For instance, for patients whose PROMs reflect mild symptoms who are considering surgery, clinicians might need to communicate to them that the surgery may not work. On the flip side, for people whose PROMs reflect more severe conditions, clinicians may need to conduct shared decision-making with them to determine whether operative or nonoperative treatment options are best. This approach helps to manage patient expectations and ultimately improves decision-making in clinical practice.

Using Patient-Powered SAINTs to Remodel Primary Services and Restore Honesty in Healthcare


John Wasson

John Wasson, M.D., Emeritus Professor of Community and Family Medicine, Emeritus Professor of Medicine, Geisel School of Medicine at Dartmouth

SAINTs (Standardized Assessment and Information Network Technology) are tools that center patient priorities in healthcare. The use of a SAINT not only improves healthcare quality, but also restores honesty in primary care by helping clinicians identify key concerns for adults with non-acute health issues. Naturally, these measures also crosswalk with attributes of PROMs and PREMs. For example, a What Matters Index (WMI) condenses many PROMs and PREMs into a very brief, immediately usable form that stratifies people into risk for future hospital or emergency services and is strong indicator of their quality of life. The WMI is based on single measures for the concepts of health confidence, bothersome pain, emotional issues, polypharmacy, and medication side effects.

The process for using a SAINT involves:

1. Adopting a small SAINT to minimize respondent burden and possibly add a question or two to explore a topic of interest. For instance, a practice could ask patients about their experiences taking GLP-1 (glucagon-like peptide-1) drugs for weight loss since significant marketing efforts have prompted numerous inquiries from overweight or obese people.
2. Focusing on standard universal needs identified by a SAINT and learning from patient experiences. In the GLP example, this might entail learning about experiences with GLPs so that real-world patient experiences may be shared with future GLP candidates.
3. Using immediately available data from a SAINT to identify improvement opportunities.
4. Keeping patients informed to nurture better services and insights.

5. Supporting practice-based research networks (PBRNs) to test hypotheses and address relevant questions efficiently.

Recently, a primary care practice completed four steps of the five-step SAINT process to provide real-world information about GLP medications. The practice's data, compared nationally, revealed similar WMI risk profiles for obese patients on GLPs. Early results trend toward lower medication effectiveness for higher-risk patients with a lower quality of life. This observation should be considered for subsequent investigations.

Based on a small sample, the proof of concept quickly generated real-world estimates of GLP effectiveness that can, in turn, be communicated to patients. The SAINT process of data gathering, and hypothesis-generating is cost-effective, does not require electronic health records (EHR) changes, and involves patients in the data collection. Instead, a medical practice can simply go to the internet, customize the SAINT, and periodically discuss real-world results with other practices. Patients do the rest and benefit from SAINT feedback and clinician actions for what matters most.

Patient-powered data are needed to counter misleading information derived from controlled trials. The SAINT approach enhances primary care by improving service delivery, providing honest information, reducing administrative burdens, and incentivizing participation in PBRNs to help to support this model.

One resource that is available is an informational website: www.honestyinhealthcare.org. This site supports the scientific exploration of patient-powered SAINTs like the very brief WMI and their potential to transform primary care. It features an interactive database for more than 150,000 adults, providing valuable insights like those illustrated in the GLP-1 example.

SAINTs are effective tools for converting proof of concept into proof of value. By involving more primary care physicians in a collaborative effort, large amounts of real-world data can be identified to determine the care that is most effective for different patients. If adopted by PBRNs, payers, and EHR vendors, this approach can increase honesty in healthcare and be monetized to benefit the common good.

Using PROMs: One Institution's Journey

Judith Baumhauer

Judith Baumhauer, M.D., M.P.H., Senior Vice Dean of Academic Affairs, University of Rochester School of Medicine & Dentistry

The University of Rochester integrates PROMs into its healthcare system to enhance patient care. There has been a great amount of growth and many wins, though there are some barriers that have prompted thoughtful consideration of the path forward.

Initially, the physical function of anterior cruciate ligament (ACL) reconstruction patients was measured using a gait map, which was time-consuming. Adoption of PROMIS—a tool that measures various symptom complexes—enabled the assessment of patients' physical function in a quick and efficient manner via an iPad in the waiting room. This revealed the potential to collect PROMs from our patients during clinic visits and led to the development of a pilot implementation program using advanced technology.

The pilot started with three specific divisions within orthopedics, using a custom platform due to a lack of suitable commercial options. Within three weeks, the pilot expanded to all orthopedic divisions, collecting data reflecting approximately 17,000 visits per month. From that came a realization that PROMs are most useful during baseline assessments and treatment plan transitions; data from patients needed to be collected when their recovery is deviating from the expected course, or their treatment plans are being changed. Data were instantaneously integrated into EHRs with an easily interpretable graph at the time of the visit for easy visualization and decision-making.

Over two years, the initiative grew organically, with other departments expressing interest. Now, seven years later, the University of Rochester has transitioned PROMs from a custom platform to the Epic EHR system and integrated them into a quality institute governance model. This initiative focused on reducing variations in provider costs and procedures, aligning recovery expectations, and using predictive modeling for patient improvement and payment models, including models for joint replacement. This system allows for site-of-service collection and a population health initiative that collects PROMIS data from all patients who have not had a visit within six months. This patient-centered approach enables the allocation of resources based on patient needs.

Epic now includes charts and graphics that reflect scores, as well as changes in the scores. Since 2015, data have been collected from more than 505,000 patients, with each domain taking, on average, 39 seconds to complete. The efficiency of this process supports better patient care and decision-making.

For example, the PROMIS physical function scores help to determine the likelihood of improvement after knee replacement surgery. If the pre-operative or baseline scores indicate that operative options, such as a knee replacement, will not yield physical function improvements, and this is what the patient is hoping to achieve, nonoperative options can then be considered. Ultimately, this reduces healthcare costs by avoiding an operation that does not align with patients' goals and surgical expectations, adding value for patients.

With all the successes, barriers still exist. The main barrier is technology usability. There is also a need for more customization, as well as education on use. This is crucial because if clinicians do not share data with their patients due to these barriers, patients will not see the necessity of completing the PROM measures. Another challenge is the burden faced by physicians who spend a significant amount of their time documenting other quality measures required for reimbursement. Many of these measures, often process measures, have not been shown to improve individualized patient outcomes or healthcare quality and value.

As such, the path forward is to align incentives, remove process measures, and recognize PROMs as a quality measure. Finally, and importantly, integrating PROMs into medical education will inform our trainees, the future healthcare workplace, on the importance, use, and effectiveness of PROMs in clinical practice.

Gaining Buy-In on PREMs and PROMs


Rachel Hess

Rachel Hess, M.D., M.S., Associate Vice President of Research-Health Sciences, University of Utah Health Sciences

As we move toward greater use of PREMs and PROMs, it is noteworthy to think about how these measures are viewed from a variety of perspectives—patients, payers, clinicians, and administrators. What does each group get, and how do they buy in? Each group has different views on implementation and value. The intent of PROMs and PREMs is to elevate patient voices, yet patients may feel discouraged in providing information if they feel it does not impact their care.

Clinicians need to promote the value of these measures so they can meaningfully engage patients in their use. A real-life example involved a sophisticated system to screen for psychiatric conditions. This system encountered issues simply because providers were unfamiliar with and generally disliked the tools. Extensive rework on assessments that entailed collecting the same data on patients took a great deal of time. This, in turn, discouraged patients, providers, and administrators from finding value in the system.

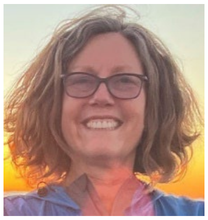
These psychiatric clinics are currently undergoing a reboot with a simpler approach that moves incrementally to meet patients and providers where they are. Administrators find the data useful, particularly for measuring patient experience with PREMs. In Utah, PREMs promote an exceptional patient experience, where a threshold is set and all facilities above that threshold are considered excellent. This encourages providers to not compete but instead work collaboratively to continuously improve.

Defining goals upfront will inform how receptive groups are to deploying PROMs and PREMs. There has been much buy-in with PREMs, which are widely recognized to enhance personalized care and ensure high standards. As for PROMs, although they are mandated for some conditions, acceptance varies.

Selecting the right tools involves balancing meaningful and pragmatic data and ensuring accessibility, simplicity, and interpretability. Also, the question exists not only how to present the data, but how to make it meaningful to individuals using the data. Both can be achieved with a lot of listening, attention, and communication.

PROMs and PREMs support patient-centered care by bringing patient experiences to the forefront, tailoring treatments, and informing a learning health system. The hope is to encourage people to use the data and include everyone—patients, providers, and caregivers—in the design and execution of these measures.

PREMs and PROMs: A Patient's Perspective



Esther Burlingame

Esther Burlingame, M.H.A., Patient Advocate

Involving patients as key partners in the use of PROMs and PREMs is crucial. These measures highlight the value of shared validated information with patients to enhance their role on the care team. Social media support groups often provide information, but patients can benefit more from validated data from their providers.

Every single patient and patient advocate group needs to know that they are not only a key part of the care team, but also the most important part of the care team. Thus, it is critical that standardized assessments such as PREMs and PROMs are shared. PROMs, for their part, need to be more widely used, and initiatives such as SAINT that share best practices are a step in the right direction.

As for PREMs, the idea of having a threshold to achieve continuous improvement is a good one, because having clinicians compete can be counterproductive. Currently, PREMs tend to be rank-based, and often, the differences in scores are tight. Interpreting PREMs scores can be complicated and lead to giving patients false impressions.

This risk of false impressions raises the larger topic of health literacy, which is so crucial to engaging patients.

Patients often do not understand the information that is provided to them and are too frightened to ask for clarification. Enhancing health literacy involves clear communication to patients about their care and outcomes—communication without medical jargon or acronyms. It also requires that providers encourage patients to communicate, "This is what matters to me." Because ultimately, these patient-reported measures should be about what matters to the patient.

Closing Remarks

Craig Umscheid

Craig Umscheid, M.D., M.S., Director of the Center for Quality Improvement and Patient Safety (CQuIPS), Agency for Healthcare Research and Quality

Thank you to the CAHPS team, Westat colleagues, and CAHPS grantees, and to everyone who participated in this event. On this World Patient Safety Day (September 17), it is important to recognize the role of patient-reported measures in enhancing quality and safety in healthcare. PREMs and PROMs are integral to amplifying the patient voice—one of the five aims of the National Action Alliance (NAA). Thank you to all for joining this event and for your efforts to ensure that patients are always heard.

Acknowledgements

Moderator for Keynote and Part I: Ron D. Hays, Ph.D., Distinguished Professor of Medicine, UCLA Division of General Internal Medicine & Health Services Research
Moderator for Part II: Dale Shaller, M.P.A., Principal, Shaller Consulting Group
Moderator for Part III: Susan Edgman-Levitan, P.A., Executive Director, John D. Stoeckle Center for Primary Care Innovation, Massachusetts General Hospital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AHRQ Publication No. 25-0015
November 2024
www.ahrq.gov