Patient-Reported Outcome Performance Measures

Current Environment
And Next Steps

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Executive Summary

Patient-reported outcome performance measures (PRO-PMs) are tools that utilize information provided by patients on their symptoms, experiences of care, quality of life, and other aspects of health and health care that can be used to assess provider performance. As the U.S. health care system embraces new value-based payment models, PRO-PMs are increasingly emphasized to ensure that the patient voice is captured in assessments of quality. Policymakers, payers, and health care providers are beginning to use PRO-PMs to inform clinical decision making, benchmark and improve quality of care, adjust provider payment, and assess the value of medical technologies.

While of increasing importance, PRO-PMs are still emerging, and there are significant challenges that must be overcome to achieve broad adoption of these measures. In this issue brief, we review the results of an environmental scan to identify existing PRO-PMs and assess their use in Medicare quality and payment programs. There are significant gaps in available PRO-PMs, stemming from particular challenges to their development and use. We highlight these challenges, as well as potential solutions for filling the gaps that leverage promising projects in the field.

Drivers

The growing emphasis on PRO-PMs has been driven by the emergence of new priorities in health care quality and care delivery. First, making health care more patient-centered is a goal of the National Quality Strategy. In patient-centered care, the patient and family are engaged as partners, and care focuses on patient preferences and desired outcomes of value to patients. A second driver is the trend toward consumerism, which focuses on increased engagement of patients in their care, including shared decision making with providers to make informed treatment decisions, self-management of their conditions, and greater financial responsibility for the cost of care. A third driver is the evolution of precision medicine, which is an approach to disease prevention and treatment that takes into account a patient's genetics, environment, lifestyle, and preferences. PRO-PMs align with these priorities by providing a consistent method for measuring outcomes from the patient perspective.
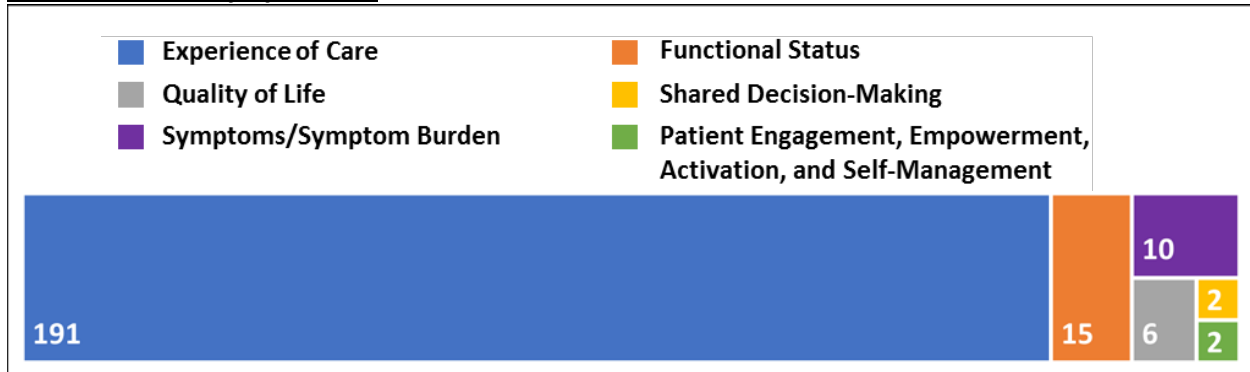
Measure Scan

To better understand the current PRO-PM landscape, we conducted an environmental scan of measure databases to identify and categorize existing PRO-PMs. We then identified measure gaps by comparing the identified measures against published reports from the Centers for Medicare & Medicaid Services (CMS) and the National Quality Forum (NQF) that highlight areas of need and priority for PRO-PMs. Finally, we assessed the use of PRO-PMs in CMS quality and payment programs to assist in understanding where there are gaps in both availability and implementation.
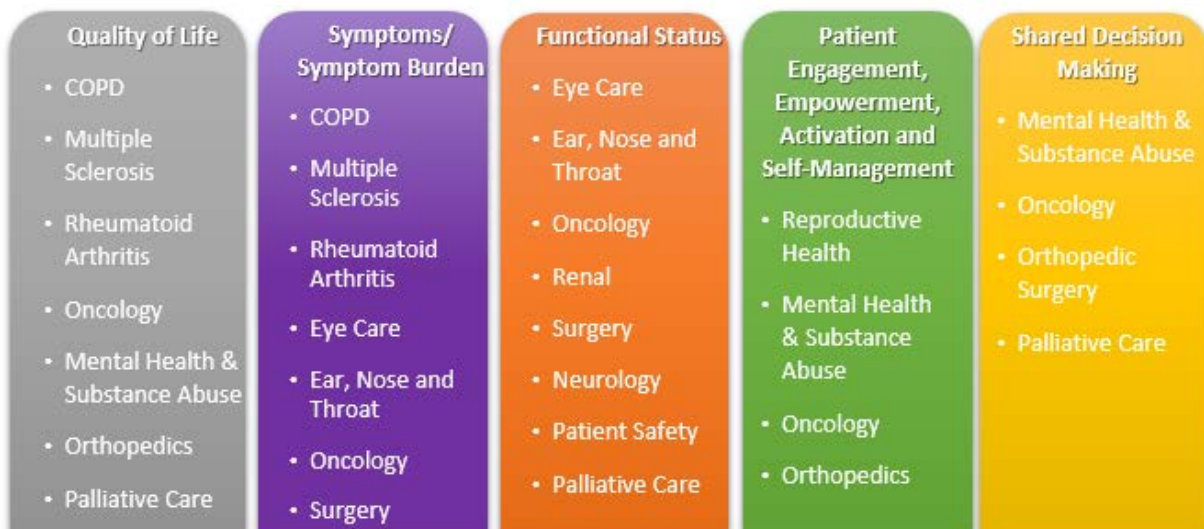
Findings

1. **Most PRO-PMs assess Experience of Care. Fewer measures are available to assess outcomes like Functional Status, Symptom Burden, and Quality of Life.** We identified a total of 226 existing PRO-PMs. Notably, 85 percent (191) of these measures are in the domain of Experience of Care. The next most commonly represented domain is Functional Status (15 measures), followed by Symptoms and Symptom Burden (10 measures), and Quality of Life (six measures). The domains of Shared Decision Making and Patient Engagement, Empowerment, Activation, and Self-Management each had only two PRO-PMs.

Measure Inventory by Domain

Legend:
- ■ Experience of Care
- ■ Quality of Life
- ■ Symptoms/Symptom Burden
- ■ Functional Status
- ■ Shared Decision-Making
- ■ Patient Engagement, Empowerment, Activation, and Self-Management

Experience of Care: 191 | Functional Status: 15 | Symptoms/Symptom Burden: 10 | Quality of Life: 6 | Shared Decision-Making: 2 | Patient Engagement: 2

2. **Use of PRO-PMs in CMS quality and payment programs is still nascent.** Of the 226 available PRO-PMs we identified, 38 (about 17 percent) are currently in use in CMS quality and payment programs. Similar to the distribution of available measures, 26 of the 38 measures in use are Experience of Care measures. These measures are in use across multiple CMS programs. There are also eight Functional Status PRO-PMs in use, all in the Merit-based Incentive Payment System (MIPS).

3. **Gaps remain in critical areas where the patient perspective is essential in driving improvements in quality.** Based on our comparison of identified measures to recent reports on measure priorities from CMS and NQF, we identified the following conditions and domains as having gaps. Gaps persist in areas where the demand for PRO-PMs has been greatest, like oncology. While Experience of Care is well covered by existing PRO-PMs, all other domains have significant gaps. Efforts to develop cross-cutting PRO-PMs that cover multiple domains and conditions are likely to be the most efficient way to fill gaps.

Quality of Life	Symptoms/Symptom Burden	Functional Status	Patient Engagement, Empowerment, Activation and Self-Management	Shared Decision Making
• COPD	• COPD	• Eye Care	• Reproductive Health	• Mental Health & Substance Abuse
• Multiple Sclerosis	• Multiple Sclerosis	• Ear, Nose and Throat	• Mental Health & Substance Abuse	• Oncology
• Rheumatoid Arthritis	• Rheumatoid Arthritis	• Oncology	• Oncology	• Orthopedic Surgery
• Oncology	• Eye Care	• Renal	• Orthopedics	• Palliative Care
• Mental Health & Substance Abuse	• Ear, Nose and Throat	• Surgery		
• Orthopedics	• Oncology	• Neurology		
• Palliative Care	• Surgery	• Patient Safety		
		• Palliative Care		

4. **Several promising initiatives are underway to advance development and use of PRO-PMs.** We identified several emerging patient-centric projects that are helping to promote the development and use of PRO-PMs. The NQF Measure Incubator™ facilitates measure development and testing through collaboration and partnership, and the majority of measures

currently in development through the Incubator are PRO-PMs. In addition, the National Institutes of Health's Patient-Reported Outcomes Measurement Information System (PROMIS) is addressing the lack of standardization of the tools used to assess patient-reported outcomes (PROs). There are also promising ongoing projects focused on systematically capturing the patient voice for the prioritization and conceptualization of PRO-PMs, including the Food and Drug Administration (FDA) Voice of the Patient and the NQF PatientsLikeMe initiatives.

Challenges and Potential Solutions

Based on our assessment of the current PRO-PM environment, we identified a series of critical challenges that are preventing more rapid development and use of PRO-PMs, as well as potential solutions to these challenges. Where possible, these solutions leverage emerging and ongoing work in the PRO-PM environment rather than proposing a completely new approach.

Development

- **Challenge:** Identifying what matters to patients is difficult to systematically assess.
  - ➤ **Solution:** Leverage efforts such as FDA Voice of the Patient and PatientsLikeMe reports to identify endpoints of interest to patients and translate them into measure concepts.
- **Challenge:** Developing and implementing PRO-PMs requires significant time and resources.
  - ➤ **Solution:** Leverage PROMIS and other resources to adapt existing patient-reported outcome measures (PROMs) and validate them in new patient populations to reduce the time and resources needed to develop both PROMs and PRO-PMs.
- **Challenge:** The process for developing PRO-PMs is not well defined.
  - ➤ **Solution:** Develop a manual or guidebook detailing the measure development process from measure concept to PRO-PM implementation.

Implementation

- **Challenge:** Using PRO-PMs at a provider level results in low measurement reliability.
  - ➤ **Solution:** Use cross-cutting PROMs and PRO-PMs across conditions, rather than using condition-specific measures.
- **Challenge:** Patient reporting requirements are burdensome and result in low response rates.
  - ➤ **Solution:** Leverage new technologies to capture PROs through apps, remote monitoring devices, and other methods.
- **Challenge:** Clinicians are skeptical of PROs due to concerns about the subjectivity of patient reporting and the resources needed for collection.
  - ➤ **Solution:** Integrate PROs into clinician workflow as a mechanism to enhance shared decision making and promote clinician understanding of patients' perspectives and needs.
  - ➤ **Solution:** Provide an on-ramp to PRO-PM adoption (e.g., gradually transition from pay-for-reporting to pay-for-performance as clinicians gain experience with PRO-PMs).
- **Challenge:** The nature of PRO-PMs creates issues of data interoperability, usability, and security. Privacy and appropriate use of PRO-PM data are key concerns for patients.
  - ➤ **Solution:** Advocate for a focus on PRO-PM data standards in key initiatives, such as the National Committee for Quality Assurance's Digital Measures Collaborative.

Background

There is growing interest in understanding the patient perspective and incorporating it into the delivery of health care. At the same time, there is increasing recognition that patients are often the best source of information on the quality of care they receive. For the patient perspective to improve quality, it must be validly and reliably measured, and measures must be used in appropriate and meaningful ways.

Performance measures are important tools for guiding, assessing, and incentivizing improvements in health care delivery and outcomes. When performance measures incorporate patient-reported outcomes (PROs), the result is a patient-reported outcome performance measure (PRO-PM). The use of PRO-PMs to assess provider performance and improve quality is well supported by existing evidence; research has shown that patient and physician perceptions of outcomes often differ, and taking patients' self-perceptions of health into account may lead to more effective interventions.[1]
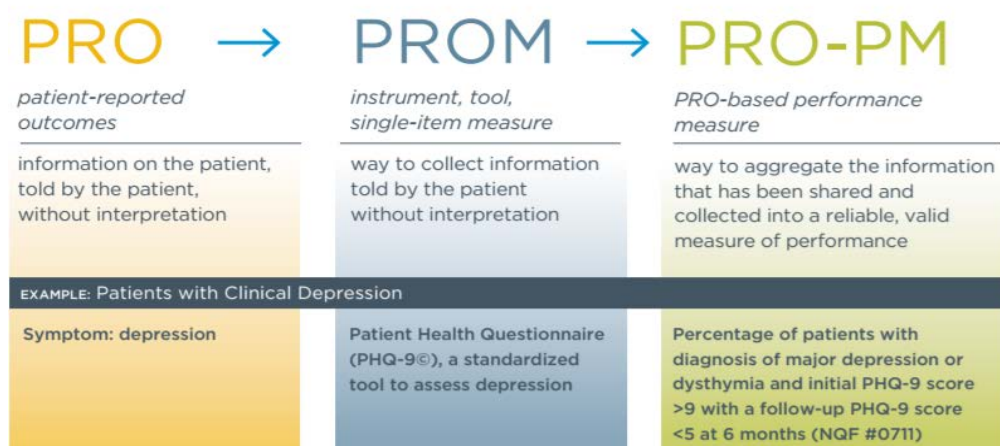
In this issue brief, we assess the current PRO-PM environment, including reviews of how PRO-PMs are being used in quality and payment programs, drivers of their use, and currently available measures. After identifying measures and mapping them to priority measure domains, we identify priority measurement gaps. Finally, we identify opportunities to fill existing measure gaps and promote the development and use of PRO-PMs.

Definitions and Progression

The terms used to refer to patient-reported information, and the relationships between different terms, are often confused and are important to review. PROs are defined as "any report of the status of a patient's (or person's) health condition, health behavior, or experience with healthcare that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else."[2] Patient-reported outcome measures (PROMs) are the instruments or tools used to capture PROs.

PRO-PMs utilize the information captured in a PROM to establish a measure of performance. Unlike process measures, which tend to capture adherence to care standards, PRO-PMs attempt to capture whether the services delivered have actually improved patient health and well-being.[3] Figure 1, which was taken from a National Quality Forum (NQF) report,[4] reviews these definitions and highlights the progression of a PRO to a PRO-PM, using reporting of depression as an example.

Figure 1. Progression of a PRO to a PRO-PM

PRO →	PROM →	PRO-PM
patient-reported outcomes	*instrument, tool, single-item measure*	*PRO-based performance measure*
information on the patient, told by the patient, without interpretation	way to collect information told by the patient without interpretation	way to aggregate the information that has been shared and collected into a reliable, valid measure of performance

EXAMPLE: Patients with Clinical Depression

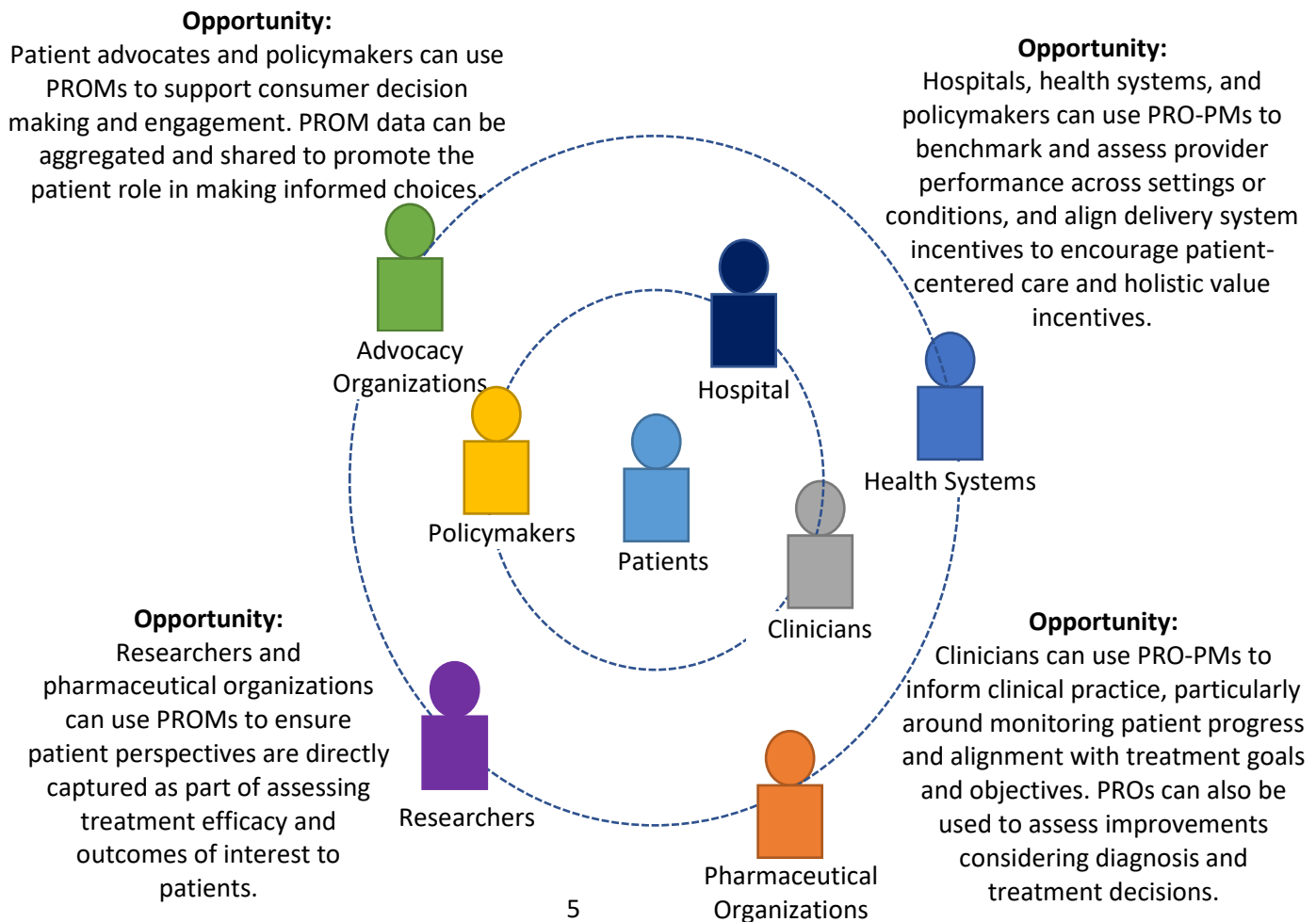| Symptom: depression | Patient Health Questionnaire (PHQ-9©), a standardized tool to assess depression | Percentage of patients with diagnosis of major depression or dysthymia and initial PHQ-9 score >9 with a follow-up PHQ-9 score <5 at 6 months (NQF #0711) |

Nuances in PRO Terminology

Importantly, the term PRO is often applied to measures that are not actually outcomes. For example, measures of shared decision making are technically process measures. However, these measures represent the patient perspective on important aspects of care, and a patient may view these processes as outcomes. In addition, measures that are based on patient reports, but are interpreted and/or recorded by a clinician or staff member, are often referred to as PROs but do not meet the strict definition.

The Role of PRO-PMs

PROs, PROMs, and PRO-PMs have a variety of potential uses by a range of health care stakeholders. As shown in Figure 2, there are numerous opportunities for incorporating the patient voice into clinical decision making to inform treatment planning, quality improvement, value-based payment, and value assessments. Policymakers and health systems can use PRO-PMs to benchmark provider performance and assess the value of care being provided from the patient perspective. At the provider level, PRO-PMs can be used for improving clinical practices and processes and monitoring patient progress toward treatment goals. PROMs and PRO-PMs can also be used by patients to make more informed decisions about where to seek care and which treatments may be preferable to others. Additionally, PROMs can be used to ensure that the patient voice is captured in assessments of the efficacy of drugs, devices, and other medical technologies.

Figure 2: Stakeholder Uses of PROMs and PRO-PMs

Opportunity:
Patient advocates and policymakers can use PROMs to support consumer decision making and engagement. PROM data can be aggregated and shared to promote the patient role in making informed choices.

Opportunity:
Hospitals, health systems, and policymakers can use PRO-PMs to benchmark and assess provider performance across settings or conditions, and align delivery system incentives to encourage patient-centered care and holistic value incentives.

Opportunity:
Researchers and pharmaceutical organizations can use PROMs to ensure patient perspectives are directly captured as part of assessing treatment efficacy and outcomes of interest to patients.

Opportunity:
Clinicians can use PRO-PMs to inform clinical practice, particularly around monitoring patient progress and alignment with treatment goals and objectives. PROs can also be used to assess improvements considering diagnosis and treatment decisions.

Advocacy Organizations

Hospital

Policymakers

Patients

Clinicians

Health Systems

Researchers

Pharmaceutical Organizations

Factors Influencing Growth in PRO-PMs

The use of PRO-PMs is a relatively recent development in U.S. health care. Patient experience of care and PROs only began to be measured in validated clinical formats in the 1980s, and their use remained low through the 2000s. The development and use of PRO-PMs based on PROs grew along with the movement toward value-based payment in the mid-2000s, and accelerated after the implementation of the Patient Protection and Affordable Care Act of 2010 (ACA).

Drivers of PRO-PMs

The growing emphasis on PRO-PMs has been driven by the emergence of new priorities in health care quality and care delivery, including patient-centeredness, consumerism, and precision medicine. These drivers are likely to continue to generate momentum for the increased development and use of PRO-PMs.

Patient-Centeredness

The ACA established a National Quality Strategy (NQS), which promotes patient-centered care as a national priority for health care quality improvement. Patient-centered care ensures that each person and family is engaged as a partner in their care. It means that performance assessments should be based not only on improved outcomes, but also on whether patients achieve their *desired* outcomes. Care should adapt readily to individual and family preferences and circumstances, including differing cultures, languages, disabilities, health literacy levels, and social backgrounds.[5]

PRO-PMs are a key mechanism for promoting patient-centeredness in health care. Historically, patients and their families have been a largely untapped resource in assessing quality. But they are the most authoritative source of information on a range of outcomes, including health-related quality of life, functional status, and symptoms and symptom burden. The use of PRO-PMs permits measurement of these outcomes, better communication between providers and their patients, and even a link between payment and performance from the patient perspective.

Consumerism

Related to patient-centeredness, a growing emphasis on health care consumerism is encouraging individuals to take a more active role in their care. This more active role includes responsibilities such as improving healthy behaviors, reviewing data on quality and cost to make more informed decisions on where to seek care, engaging in shared decision making with providers, and adhering to care plans and treatment regimens. As patients become more engaged in their care, they may be better positioned and more frequently prompted to provide more informed and detailed responses to PROMs capturing the patient perspective. New technologies are making it easier for patients to report data and monitor their health, as well as become active participants in the quality of their care.

Increased patient cost-sharing is encouraging consumerism. The growing use of high-deductible health plans and health savings accounts is forcing patients to consider the cost of care. Notably, there is evidence that their use may have negative impacts, with low-income patients forgoing needed services.[6] Value-based benefit designs, on the other hand, provide incentives for the use of providers and services deemed to be high-value, rather than just low-cost.

Precision Medicine

Patient-centered care is being reinforced by new models of care focused on tailoring care to a patient's unique profile. Precision medicine is an emerging approach to disease prevention and treatment that

incorporates a patient's genetics, environment, lifestyle, and preferences. It has the potential to generate more accurate diagnoses, more rational disease prevention strategies, better treatment selection, and the development of novel and targeted therapies. These approaches require increased engagement from patients, in line with the recent emphasis on consumerism.

The focus on precision medicine further increases the need for PRO-PMs. Precision medicine requires better understanding of patient preferences, as well as functional status, symptoms, and other domains captured by PROMs. Moving toward precision medicine also requires increased patient engagement and shared decision making, both of which are important outcomes most appropriately reported by patients. Moreover, traditional process-focused quality measures with broad numerators and denominators are unlikely to be sufficient in the new era of precision medicine. Measures that assess key aspects of patient preferences, including functional status and symptom abatement goals, may promote alignment of desired outcomes and consequently broaden denominators and use across populations with similar treatment goals.

Recent Policy Milestones

As these drivers have placed greater emphasis on PRO-PMs, policymakers have facilitated their development and use. Since the ACA was passed into law and implemented, government agencies and health policy organizations have released landmark reports that have provided goals, principles, and strategies for PRO-PM development and implemented key initiatives to promote their development and use:

- **2011: Department of Health and Human Services—National Quality Strategy.** The NQS serves as a "blueprint to improve the delivery of healthcare services, patient health outcomes, and population health."[7] Released in March 2011 and updated yearly, the NQS identifies three overarching aims: better care, healthy people and communities, and affordable care. It also outlines six priority areas for collective action to drive toward a high-value health system: health and well-being, prevention and treatment of leading causes of mortality, person- and family-centered care, patient safety, effective communication and care coordination, and affordable care.

- **2013: NQF—PROs in Performance Measurement Report.** With funding from the Department of Health and Human Services, NQF convened a multi-stakeholder panel to focus on the development, endorsement, and implementation of PRO-PMs. In the report, NQF stated that patient and family engagement is a key component of a strategy to achieve a high-quality, affordable health system. Members of the expert panel conceptualized guiding principles for selecting PROMs in the context of performance measurement: psychometric soundness, person-centeredness, meaningfulness, amenability to change, and ability to be implemented. Beyond these principles, NQF laid out the critical steps for generating the evidence needed to meet NQF criteria for endorsement.

- **2015: RTI International—Patient-Reported Outcomes in Performance Measurement Report.** This report addresses the major methodological issues related to the selection, administration, and use of PROMs for individual patients in clinical practice settings. The report also highlights best practices for identifying and using PROMs to calculate PRO-PMs.

- **2016: CMS—Person and Family Engagement Strategy.** CMS developed this strategy to share the agency's vision for person and family engagement, and to encourage the entire health care community to incorporate the principles into their work practices. This report serves as a guide for individuals and groups looking to incorporate engagement principles into clinical practice, program development, community health initiatives, and other areas where shared decision making and appreciation of individual values are important. This document also provides tools and methods for individuals to become more engaged in their care.

- **2016: Accenture—Conceptualizing a Data Infrastructure for the Capture, Use, and Sharing of Patient-Generated Health Data in Care Delivery and Research through 2024.** The recent proliferation of consumer health technologies, such as online questionnaires, mobile applications, and wearable devices, has increased the frequency, amount, and types of patient-generated health data (PGHD) available. These advances enable patients and their caregivers to independently and seamlessly capture and share their health data electronically with clinicians and researchers from any location. To contribute to the development of an overall PGHD policy framework, this white paper, funded by the Office of the National Coordinator for Health IT, describes key opportunities and challenges for realizing the potential of PGHD use and offers relevant enabling actions that could further enhance PGHD capture, use, and sharing for health care delivery and research in the United States. [8]

PRO-PM Measure Scan

To better understand the current state of PRO-PM use, we conducted an environmental scan of existing measures, categorized them by measure domain, and identified gaps in priority areas. In this section, we review the methods used in our scan, including the taxonomy we used to categorize measures into domains. We then review the findings by measure domain and identify critical measure gaps.

Methods

The environmental scan included review of existing measure databases, including the NQF Quality Positioning System, the Agency for Healthcare Research and Quality's (AHRQ's) National Quality Measures Clearinghouse, and the CMS Measures Inventory. In our initial search, we used the term "PRO-PM" and searched by PRO-PM criteria (e.g., measure type = outcome; data source = patient; data source = patient survey). We then broadened the search to include terms from an array of PRO-PM domains (Table 1). The taxonomy presented in Table 1 is a synthesis of different measure taxonomies in use for PRO-PMs and represents the most commonly included measure domains.
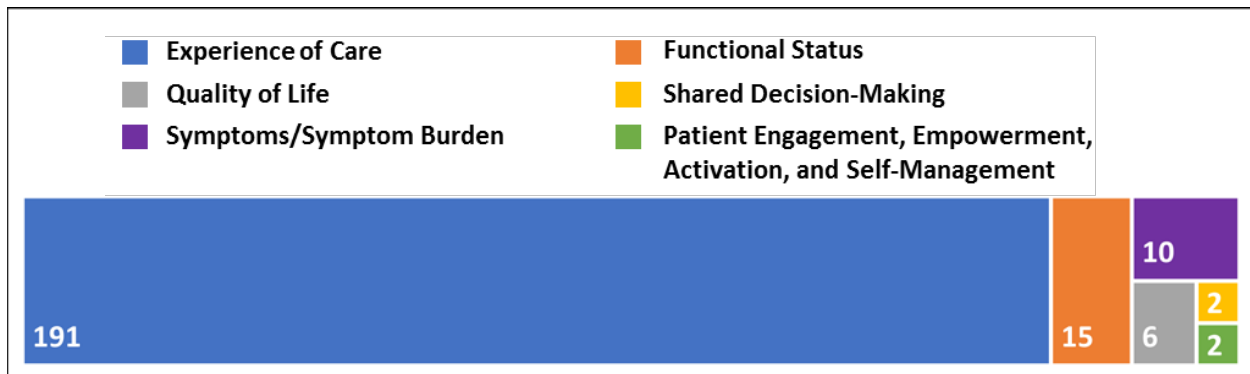
This search method resulted in a substantial inventory of measures. We then conducted reviews of measure specifications to ensure identified measures met PRO-PM criteria. Specifically, we ensured that patient or caregiver completion of a PROM was the data source, rather than use of an assessment instrument completed by a clinical team. We included measures that met all criteria but were technically process measures, such as measures of shared decision making.

- Experience of Care
- Functional Status
- Quality of Life
- Shared Decision Making
- Symptoms and Symptom Burden
- Patient Engagement, Empowerment, Activation, and Self-Management

To identify measure gaps and potential areas of interest for future PRO-PM development, we assessed the identified measures against information on measure priorities from the field. The measure priorities were identified by reviewing all NQF consensus development project reports from August 2016 to August 2017, reports which include information on multi-stakeholder panels' areas of interest for PRO-PM development. The CMS Measures Under Development list and 2017 Measure Development Plan were also reviewed.

Findings

We identified a total of 226 measures in our measure scan. Notably, the distribution of measures across the domains varies significantly, with about 85 percent of the measures falling into the patient experience domain. All other domains have very few fully specified PRO-PMs with a clear numerator and denominator. Notably, emerging bodies of work, such as PROMIS and International Consortium for Health Outcomes Measurement standard sets that are not included in measure databases, were not captured in our search. In addition, this count does not include PROMs used to assess PROs. Figure 3 presents the overall findings by domain, and we then summarize findings in each domain.

Figure 3. Measure Inventory by Domain

Legend: Experience of Care; Functional Status; Quality of Life; Shared Decision-Making; Symptoms/Symptom Burden; Patient Engagement, Empowerment, Activation, and Self-Management

191 | 15 | 6 | 2 | 10 | 2

Experience of Care

Patient experience encompasses the range of interactions that patients have with the health care system, including with their health plans and providers. The terms "patient satisfaction" and "patient experience" are often used interchangeably, but they do not have the same meaning. Patient experience assesses whether the patient received an appropriate service or standard of practice, while patient satisfaction assesses whether that patient's personal expectations were met.[9] Satisfaction can

be considered one component of patient experience. Experience of Care measures are often aimed at specific patient populations and/or settings of care.

We identified 191 Experience of Care measures in our scan. These measures were identified primarily in the Consumer Assessment of Healthcare Providers and Systems (CAHPS®) family of surveys. Table 2 identifies the patient populations, settings of care, and specific focus areas of these Experience of Care measures.

Table 2: Experience of Care Focus Areas

CAHPS® Family		Non-CAHPS®
Health Plan	Clinician & Group	Young Adult
Cancer Care	Surgical Care	Bereaved Family
Child Hospital	Dental Plan	Care Transitions
Experience of Care and Health Outcomes (ECHO)—Behavioral Health	American Indian	Inpatient Psychiatric Care
Nursing Home	Adult Hospital	Inpatient Pediatric Care
Accountable Care Organizations (ACOs) Participating in Medicare Initiatives	Home- and Community-Based Services	Patient-Centered Medical Homes
Group Practices Participating in the Physician Quality Reporting System	Hospice	Home Care
Home Health Care	Outpatient and Ambulatory Surgery	Homeless
In-Center Hemodialysis		Dental Plans
		Skilled Nursing Facilities

Functional Status

Functional status may be defined as "an individual's ability to perform normal daily activities required to meet basic needs, fulfill usual roles, and maintain health and well-being."[10] Measures are counted under this domain if they are confirmed to be patient-reported and incorporate functional status or activities of daily living.

While understanding patient functional status is important for understanding and addressing patient needs, only a small number of PRO-PMs are available in this domain. We identified 15 functional-status PRO-PMs. The majority focused on post-operative status for musculoskeletal surgical procedures (e.g., back surgery, hip surgery, knee surgery) or physical therapy. It should be noted that there are many additional measures of functional status that are clinician-assessed. These measures are not included in this count.

Quality of Life

According to the Centers for Disease Control and Prevention (CDC), the definition of health-related quality of life from the individual's perspective includes that individual's perceptions of physical and mental health perceptions (e.g., energy level, mood), as well as ratings of health status.[11] However, even with this broad definition, the number of measures identified in this domain was low. This search resulted in the identification of six measures where quality of life is specifically noted in the measure title or specifications. For example, the Health-related Quality of Life in COPD [chronic obstructive pulmonary disease] patients before and after Pulmonary Rehabilitation measure assesses the number of

patients with clinician-diagnosed COPD who have participated in pulmonary rehabilitation and have been found to increase their HRQOL score by 1.0 points, as measured by the Chronic Respiratory Disease Questionnaire or a similar tool. The Medicare Health Outcomes Survey also includes measures of quality of life such as the percentage of members whose health status was "better than expected," "the same as expected," or "worse than expected" at the end of a two-year period.

Shared Decision Making

The National Quality Partners Shared Decision Making Action Team defines shared decision making as "a process of communication in which clinicians and patients work together to make optimal healthcare decisions that align with what matters most to patients."[12] Shared decision making has significant potential to improve patient experience and engagement, and it has recently been identified as a necessary standard of care for all patients.

Despite the growing interest in understanding the impact of shared decision making on outcomes, only two measures were identified in our scan: Shared Decision Making Process (Massachusetts General Hospital) and Informed, Patient Centered Hip and Knee Replacement Surgery (Massachusetts General Hospital) There are components of shared decision making in some CAHPS® instruments and other satisfaction surveys, but none of these PROMs have been transformed into PRO-PMs.

Symptoms/Symptom Burden

Our scan included specific symptoms, such as pain and fatigue, as well as symptom burden. We identified only 10 PRO-PMs in this domain. As with functional status, the vast majority of measures of symptoms and symptom burden are not fully patient-reported. For example, in the post-acute care setting, a number of functional status and symptom measures are reported through the completion of patient assessments as reported by clinicians. These assessments require some engagement of patients, but they are administered and reported by clinical staff.

Patient Engagement, Empowerment, Activation, and Self-Management

As with clearly defining patient experience, the concepts of engagement, empowerment, activation, and self-management are complex. There is significant overlap between these areas, and the goal of all the areas is increasing patients' involvement in their health care. These concepts are best assessed by patient report, yet we found only two PRO-PMs that clearly focused on any of these areas. The measures found are Gains in Patient Activation Scores at 12 months (Insignia Health) and Adolescent Assessment of Preparation for Transition to Adult-Focused Health Care.

Use of Measures in CMS Programs

In addition to identifying available measures, we reviewed their use in CMS quality and payment programs. Table 3 below lists the measures in use by measure domain. Out of the 226 available PRO-PMs, 38 (17 percent) are currently in use in CMS programs. As shown in the table, PRO-PMs are in use across several different programs and settings of care, including hospital programs, post-acute care programs, and the Merit-based Incentive Payment System (MIPS) for physicians.

Like the distribution of available measures, a large majority of the measures in use (about 69 percent) are from the Experience of Care domain. Most of the Experience of Care domain measures in use are CAHPS measures. The Functional Status domain has the second-largest number (seven measures) in use, all of which are used in MIPS.

Table 3. Measures in Use in CMS Programs

Measure Title	Program Usage
Experience of Care	
Hospital CAHPS	Hospital Compare, HIQRP, HVBP
Percentage of adult inpatients who reported how often their doctors communicated well	Hospital Compare, HIQRP, HVBP
Percentage of adult inpatients who reported how often the hospital staff communicated well about new medications	Hospital Compare, HIQRP, HVBP
Adult inpatients' overall rating of this hospital	Hospital Compare, HIQRP, HVBP
Percentage of adult inpatients who reported how often their room and bathroom were kept clean	Hospital Compare, HIQRP, HVBP
Percentage of adult inpatients who reported how often the area around their room was quiet at night	Hospital Compare, HIQRP, HVBP
Percentage of adult inpatients who reported how often the hospital staff was responsive to their needs	Hospital Compare, HIQRP, HVBP
Percentage of adult inpatients who reported how often their nurses communicated well	Hospital Compare, HIQRP, HVBP
Percentage of adult inpatients who reported whether they would recommend this hospital to their friends and family	Hospital Compare, HIQRP, HVBP
3-Item Care Transition Measure	Hospital Compare, HIQRP, HVBP
CAHPS® Home Health Care Survey (experience with care)	HH QRP, HHVBP
Percentage of adult home health care patients who reported their experiences with their home health care provider's patient care	HH QRP, HHVBP
Percentage of adult home health care patients who reported how well their home health care provider communicated with patients	HH QRP, HHVBP
CAHPS Clinician & Group Surveys—Adult	MIPS, Physician Compare
CAHPS Clinician & Group Surveys—Child	MIPS, Physician Compare
CAHPS Health Plan Survey, Version 5.0 (Medicaid and commercial)	Medicaid, QHP QRS
CAHPS for ACOs (experience with care, shared decision making, health and functional status)	ACO MSSP
In-Center Hemodialysis CAHPS Survey	Comprehensive End-Stage Renal Disease Care Model
Percentage of caregivers who reported that their family member received the best hospice care possible on the CAHPS Hospice Survey	HQRP
Percentage of caregivers who reported that they would recommend this hospice to their family and friends on the CAHPS Hospice Survey	HQRP
Percentage of caregivers who reported that they got emotional and religious support on the CAHPS Hospice Survey	HQRP
Percentage of caregivers who reported that the hospice team communicated well on the CAHPS Hospice Survey	HQRP
Percentage of caregivers who reported that their family member got timely care on the CAHPS Hospice Survey	HQRP

Percentage of caregivers who reported their family member got help for symptoms on the CAHPS Hospice Survey	HQRP
Percentage of caregivers who reported that their family member was treated with respect on the CAHPS Hospice Survey	HQRP
Percentage of caregivers who reported that they got hospice care training on the CAHPS Hospice Survey	HQRP
Functional Status	
Functional status change for patients with hip impairments	MIPS
Functional status change for patients with lumbar impairments	MIPS
Functional status change for patients with shoulder impairments	MIPS
Functional status change for patients with elbow, wrist, and hand impairments	MIPS
Functional status change for patients with knee impairments	MIPS
Functional status change for patients with foot and ankle impairments	MIPS
Functional status change for patients with general orthopedic impairments	MIPS
Cataracts: Improvement in patient's visual function within 90 days following cataract surgery	MIPS
Patient Engagement, Empowerment, Activation, and Self-Management	
Percentage of adult inpatients who reported whether they were provided specific discharge information	Hospital Compare, HIQR, HVBP
Symptoms and Symptom Burden	
Depression remission at six months	MIPS,
Depression remission at 12 months	MIPS, ACO MSSP
Percentage of adult inpatients who reported how often their pain was controlled	Hospital Compare, HIQR, HVBP
Abbreviations HCAHPS (Hospital Consumer Assessment of Healthcare Providers and Systems), HIQR (Hospital Inpatient Quality Reporting), HVBP (Hospital Value-Based Purchasing), CAHPS (Consumer Assessment of Healthcare Providers and Systems), HHQR (Home Health Quality Reporting), HHVBP (Home Health Value-Based Purchasing), MIPS (Merit-based Incentive Payment System), QHP QRS (Qualified Health Plan Quality Rating System), ACO (Accountable Care Organization), ACO MSSP (Accountable Care Organization Medicare Shared Savings Program), HQR (Hospice Quality Reporting)	

Due to decisions and assumptions about what measures to include in the search and how to define the measure domains, our results may differ from other scans and inventories of PRO-PMs, such as the NQF Quality Positioning System or the AHRQ Quality Measures Clearinghouse. However, while the absolute count of number of measures may be different, the pattern of PRO-PMs across the domains is similar.

An exception is patient experience, which is a domain that has seen significant debate in the health care quality community regarding whether it should be considered a PRO. NQF considers patient experience measures to be PRO-PMs, while the AHRQ Quality Measures Clearinghouse does not. Nonetheless, recognizing the importance of these aspects of care and how they may affect quality, we included Experience of Care as a PRO-PM domain.
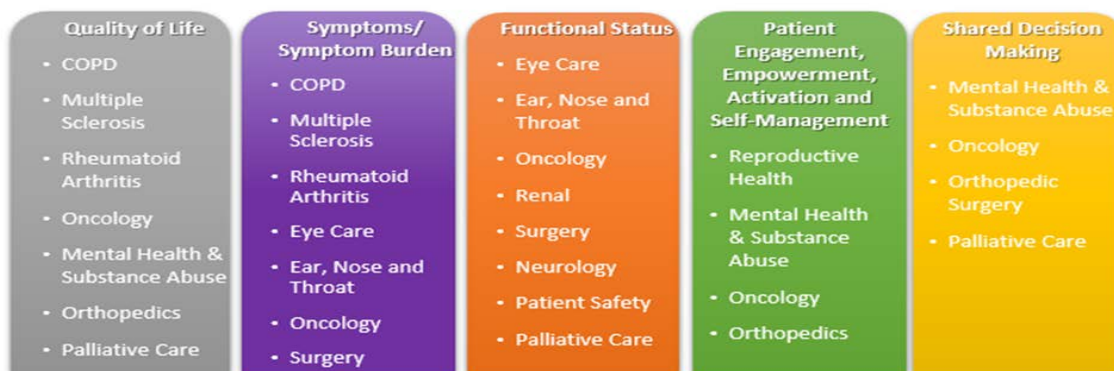
CMS Quality Improvement Activities

Improvement activities are those that improve clinical practice or care delivery and that, when effectively executed, are likely to result in improved outcomes. CMS believes improvement activities support broad aims within health care delivery, including care coordination, beneficiary engagement, population management, and health equity. In the 2018 Quality Payment Program (QPP) Final Rule, the agency finalized improvement activities to promote the collection of PROMs and reporting via clinician registries. In addition, CMS modified and expanded the proposed criteria list to also include: (1) improvement activities that focus on meaningful actions from the person and family's point of view, and (2) improvement activities that support the patient's family or personal caregiver. One example of progress in use of PROMs in the QPP is the Achieving Health Equity Improvement Activity: Promote Use of Patient-Reported Outcome Tools, which is described as: *Demonstrate performance of activities for employing PRO tools and corresponding collection of PRO data such as the use of PHQ-2 or PHQ-9, PROMIS instruments, patient-reported Wound-Quality of Life, patient-reported Wound Outcome, and patient-reported Nutritional Screening*[13].

Measure Gaps

There has been gradual progress in the development and use of PRO-PMs. As noted in our findings, the area with greatest depth and availability of measures is the Experience of Care domain. The expanding number of patient experience surveys for specific settings ensures patients and consumers have the opportunity to report their experiences with health care. These surveys cover topics that are important to consumers and focus on aspects of quality that consumers are best qualified to assess, such as the communication skills of providers and ease of access to health care services.

While the Experience of Care domain is well populated with measures, the other domains have significant gaps. We reviewed NQF Standing Committee reports, NQF Measures Application Partnership reports, and the CMS Quality Measure Development Plan, all of which identify areas of need and priority for future measure development. These reports tend to identify measure gaps, and opportunities for measure development, in specific conditions and patient populations; we have organized (in Figure 4) the specific PRO domains identified as most important for conditions with remaining measurement gaps. These domains provide some prioritization for where measure developers may want to focus measure conceptualization and development. The development of cross-cutting measures that fill gaps in multiple domains and conditions is likely the most efficient and effective way to fill gaps.

Figure 4. Measure Gaps by Domain

Quality of Life	Symptoms/ Symptom Burden	Functional Status	Patient Engagement, Empowerment, Activation and Self-Management	Shared Decision Making
• COPD	• COPD	• Eye Care	• Reproductive Health	• Mental Health & Substance Abuse
• Multiple Sclerosis	• Multiple Sclerosis	• Ear, Nose and Throat	• Mental Health & Substance Abuse	• Oncology
• Rheumatoid Arthritis	• Rheumatoid Arthritis	• Oncology	• Oncology	• Orthopedic Surgery
• Oncology	• Eye Care	• Renal	• Orthopedics	• Palliative Care
• Mental Health & Substance Abuse	• Ear, Nose and Throat	• Surgery		
• Orthopedics	• Oncology	• Neurology		
• Palliative Care	• Surgery	• Patient Safety		
		• Palliative Care		

Promising PRO-PM Projects

Although there are significant gaps in PRO-PMs, interest in their development and use remains high. A number of ongoing and emerging projects have significant potential to spur increased development of PRO-PMs to fill current gaps in measures. These projects build on the previous foundational work on PRO-PM methodological issues. Shared decision making and capturing the patient voice earlier in the development process are areas of particular focus, which is a promising sign that the future of PRO-PMs will only increase the emphasis on patient-centeredness.

Table 4: Emerging PRO-PM Projects

Topic	Organization	Overview
Measure Development	National Quality Forum Measure Incubator™	The NQF Measure Incubator™ is an innovative effort that facilitates efficient measure development and testing through collaboration and partnership. It addresses important aspects of care for which quality measures are underdeveloped or non-existent. A key focus of the Measure Incubator is the identification and incubation of PRO-PMs, and the majority of measures currently in the Incubator are PRO-PMs.[14]
Measure Implementation and Standardization	Patient-Reported Outcomes Measurement Information System	PROMIS® is a publicly available system of highly reliable, precise measures of patient-reported health status for physical, mental, and social well-being. This web-based resource can be used to measure health symptoms and health-related quality-of-life domains such as pain, fatigue, depression, and physical function, which are relevant to a variety of chronic conditions, including cancer. PROMIS has the goal of addressing the lack of standardization in PROs and PROMs, and it is already generating results through increased standardization.[15]
	The International Consortium for Health Outcomes Measurement	The mission of ICHOM is to define global standard sets of outcome measures that matter to patients for the most relevant medical conditions and to drive adoption and reporting of these measures worldwide. The role of ICHOM working groups is not to devise new outcomes measures but to agree on which measures are highly reliable, valid, and informative. These standards help put providers, payers, patients, and information technology vendors worldwide on a common path to making implementation of outcomes measurement easier and more efficient. Organizations may collect additional

		measures, but everyone is encouraged to deploy the minimum set.
Shared Decision Making	**National Quality Forum National Quality Partners™**	The National Quality Partners (NQP) Shared Decision Making Action Team is made up of 20 leaders and experts committed to making shared decision making the standard of patient care. The NQP Action Team published a Shared Decision Making Action Brief in October 2017, which highlights the fundamentals and contextual factors of shared decision making. The NQP Action Team will also release a Shared Decision Making Playbook in March 2018 that will identify best practices and practical solutions to common barriers, and will help clinicians embed shared decision making throughout the continuum of care.[16]
	CollaboRATE: Dartmouth Institute for Health Policy and Clinical Practice	This research group is focused on implementation of patient engagement and shared decision making and measuring them in routine practice. Measuring the level of engagement and shared decision The team developed CollaboRATE, a patient-reported measure of shared decision making, to enable assessment of level of engagement and shared decision making in clinical encounters and from the patient perspective. CollaboRATE contains three brief questions that patients or their representatives complete following a clinical encounter. CollaboRATE is suitable for use both in research and in routine health care delivery.[17]
Capturing the Patient Voice	**NQF and PatientsLikeMe®**	The Robert Wood Johnson Foundation funded PatientsLikeMe, in partnership with NQF, to evaluate using feedback from online patient communities to inform quality measures for improving care in critically important clinical areas. Recently, PatientsLikeMe analyzed data from its multiple sclerosis (51,000 members), COPD (2,500 members), and rheumatoid arthritis (10,000 members) communities to better understand health-related quality of life and functional outcomes. Members of these communities also provided feedback on specific tools used to collect PRO data. Guidance from patients indicated that tools available for clinicians to collect PROs do not use language that patients would use to describe common symptoms, presenting an opportunity for improvement.[18]

	Food and Drug Administration (FDA) Patient-Focused Drug Development	The FDA's Patient-Focused Drug Development initiative is a commitment under the fifth authorization of the Prescription Drug User Fee Act (PDUFA V) that aims to systematically gather patients' perspectives on their condition and available therapies to treat their condition. As part of this commitment, the FDA is holding at least 20 public meetings, each focused on a specific disease area. The Voice of the Patient reports will summarize the input provided by patients and patient representatives at each of these public meetings.[19]

Challenges and Potential Solutions

As we assessed the current PRO-PM environment, we identified a number of critical challenges that are affecting further progress in the development and use of PRO-PMs. These challenges have been categorized into development challenges and implementation challenges. We summarize each of these challenges below and recommend potential solutions for overcoming barriers and promoting advances in PRO-PM development and implementation. Rather than propose only new solutions that have not been tested, we sought to identify promising innovative work already underway that has the potential to address current challenges.

Development Challenges	
Measuring What Matters to Patients	**Challenge:** For PRO-PMs to achieve their goal of incorporating the patient voice in measurement, the PROMs and PRO-PMs used must focus on endpoints that are important to patients. However, it can be difficult to systematically assess patient priorities and prioritize among measure concepts for development. Focus groups and interviews are useful in PROM development, but additional information is helpful prior to that stage of development to understand what potential endpoints are of greatest interest and relevance to patients.
	Potential Solution: The FDA's Voice of the Patient Reports and PatientsLikeMe are intended to systematically summarize patient perspectives on their condition and available therapies to treat their condition. These publicly available reports could be used by measure developers to translate patient-identified endpoints of interest into PROMs and PRO-PMs. Moreover, they can be used by drug and device manufacturers to identify endpoints for integration into clinical research trials, and create alignment between clinical trial data and PRO-PMs.
Ill-Defined Development Process	**Challenge:** PRO-PM development requires additional steps compared to the traditional measure development process, but these steps are not well-defined and are often unclear to measure developers. The process of transforming a PROM into a PRO-PM is particularly ill-defined. NQF has published reports on

	PRO-PM methodology and a guidebook for endorsement consideration, but the guidebook does not include detailed information on PRO-PM development. Similarly, in the CMS Measure Development Plan, PRO-PM development, endorsement, and implementation are not discussed in great detail.
	Potential Solution: A manual or guidebook specifically detailing how a PRO goes from measure concept to PRO-PM implementation, and the steps required to satisfy existing measure criteria, would lay the foundation for developers to pursue consistent and standardized approaches. In addition, NQF has engaged in a number of PRO-PM Incubator projects and has evaluated PRO-PMs for endorsement through its Consensus Development Process. A report that summarizes lessons learned and how to overcome challenges in PRO-PM development would be of great value to measure developers.
Time and Resources	**Challenge:** PRO-PM development is resource-intensive, typically requiring more time and financial resources than the development of a quality measure that is not patient-reported. The additional time and resources are needed for the step of developing and/or validating the PROM prior to developing and validating the PRO-PM. In total, the time needed to develop a sound evidence base, develop and test a PROM, and develop and test a PRO-PM can exceed three to five years.
	Potential Solution: Rather than starting from scratch to develop a new PROM from which to derive a new PRO-PM, measure developers can leverage and adapt existing PROMs. In many cases, existing PROMs do not have to be substantially modified, but, rather, they can be tested and validated in a new population. While this option does not replace all development tasks, it can substantially reduce development time and resources. PROMIS can be better leveraged to identify and apply PROMs to new populations, as well.

Implementation Challenges	
Narrow Patient Populations and Low Measure Reliability	**Challenge:** There is significant interest in using PRO-PMs in provider-level accountability programs. At the same time, there has been emphasis on using PRO-PMs in condition-specific patient populations. While these priorities align with the goal of increasing patient-centeredness, small population sizes introduce measure reliability issues. When patient populations become too narrow, reliability is low, and it becomes increasingly likely that measure results are driven by chance rather than actual performance.
	Potential Solution: Use of cross-cutting PROMs and PRO-PMs within and across conditions will avoid this situation while maintaining a patient-centered approach. Through PROMIS and other initiatives, PROMs are increasingly being standardized and validated for use in multiple conditions and patient

	populations, although they need to be translated into PRO-PMs for gap areas. For example, a common Symptom Burden PROM that has been validated in multiple patient populations could be assessed for patients with multiple conditions being seen by the same primary care physician, and the results could be aggregated into a single PRO-PM that accounts for patient population differences in its scoring methodology, as needed.
Survey Fatigue and Low Response Rates	**Challenge:** With the ongoing interest in gaining the patient perspective, multiple patient questionnaires and surveys are being distributed at every level of the health care system. For example, patients with end-stage renal disease may be asked to answer a quality-of-life survey from their dialysis facility, the in-center hemodialysis CAHPS survey from their dialysis facility, a health outcomes survey from their health plan, and a provider-level survey from their nephrologist or other provider. Survey fatigue is a growing issue, and it may result in low patient response rates. Low survey responses in turn provide an even greater threat to PRO-PM reliability. Poor survey response also results in health care providers contracting with survey vendors who may make multiple attempts to reach patients, which represents a cost burden for providers while exacerbating survey fatigue for patients and their families.
	Potential Solution: Rapidly evolving technology and the ability to capture PGHD directly from patients are facilitating growth and use of PROMs and PRO-PMs, and may help address issues of survey fatigue and low response rates. The increasing number of smartphones, mobile applications, and remote monitoring devices, coupled with providers' deployment of electronic health records (EHRs), patient portals, and secure messaging, offer innovative ways to connect patients and providers and to strengthen patient engagement in their health and health care.[20] As new technologies continue to make it easier for patients to report PROs, and technology is available to automate the calculation of PRO-PMs, reporting burdens for patients and providers will continue to decrease.
Provider Acceptance	**Challenge:** Physicians, and to a lesser extent other providers, have voiced skepticism of the use of PROs and PROMs in clinical practice.[21] They often view their own assessments of symptoms, quality of life, functional status, and other measure domains as more objective and consistent than assessments by patients. They may view the value of PROs as low and not outweighing the time and financial resources required for their collection. This skepticism may affect the uptake and use of PROs and PROMs and ultimately negatively affect the validity and reliability of PRO-PMs.
	Potential Solution: Integrating PRO collection into the workflow may help to address the concerns about subjectivity and required resources. A recent study found that, once physicians began collecting PROs, they quickly realized the benefit. In interviews, physicians reported that PROs improved satisfaction with

	their practice, resulted in better physician-patient relationships, and improved workflow efficiency. They also said that collecting PROs made it easier to have difficult conversations and elicit patient preferences.[22]
Lack of Data Standards and Interoperability	**Challenge:** Whether PGHD comes from surveys or other patient-reported instruments, or from mobile applications or other new technologies, the U.S. health data ecosystem is already challenged with issues such as interoperability, usability, and security. As the health system strives for interoperability and accessibility of clinical data, there is also a need to plan for integration of PGHD with the same goals of standardization and usability. In addition, to gain patient trust for sharing of information, the system needs to ensure the privacy and security of patient-generated data.
	Potential Solution: The National Committee for Quality Assurance has initiatives in place to improve and standardize electronic data collection, including the Digital Measures Collaborative and its yearly Digital Quality Summit, which is co-sponsored with Health Level Seven. It is anticipated that emerging technology standards for quality reporting, such as the Fast Healthcare Interoperability Resources® standard, will play a major role in breaking down barriers to interoperability. Clinical Quality Language will harmonize standards between electronic clinical quality measures and clinical decision support. However, PRO-PMs and the standards needed for the accurate and secure reporting of PGHD have not been a major focus of these and other similar initiatives to date. There may be opportunities to encourage a greater focus on PRO-PM standards and interoperability.

Conclusion

PRO-PMs are a highly valuable tool for integrating the patient perspective into assessments of quality and provider performance. They have utility and potential uses across the health care system. The development and use of PRO-PMs are being driven by new priorities in health care, including patient-centeredness, consumerism, and precision medicine, and policies and guidance from federal agencies and leading organizations such as NQF.

While there is great interest and momentum behind the use of PRO-PMs, their development and use have been limited. Of 225 available PRO-PMs, 191 are in the domain of Patient Experience. Only about 16 percent of the available PRO-PMs are currently in use in CMS quality and payment programs, and, again, most are Experience of Care measures. There are critical gaps in PRO-PMs, including measures of Symptoms and Symptom Burden, Functional Status, Quality of Life, and other domains in a number of priority clinical areas, including oncology, chronic conditions, and palliative care.

To address these gaps, proponents of PRO-PMs need to focus on the pressing challenges to their development and implementation. There are a number of opportunities to build on methodological reports, address barriers, and move toward increased measure development and implementation.

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