2014 Dialogue Series /

A Multi-Stakeholder Vision for Patient-Centered Measurement in New Payment and Delivery Models

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Thank You to Our Co-Sponsors:

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Executive Summary

In light of concerns over the rising costs of healthcare, many policymakers and healthcare stakeholders have shown increased interest in reforms that contain costs while improving quality. As new payment and delivery models have proliferated, patient-centeredness has emerged as a key component of high-value care to ensure that patient perspectives inform the decision-making processes of healthcare stakeholders, and that all activities are anchored in the aim to improve outcomes for patients. This shift has led to the search for patient-reported outcomes (PRO) measures that assess the extent to which our healthcare system is keeping the patient at the center.

Avalere brought together leaders from the patient, payer, health information technology, product developer, provider, and research communities to prioritize the development and implementation of PRO measures in new payment and delivery models. The Dialogue Series resulted in the following recommendations:

1. Supplement existing PRO-related efforts by establishing a national measure development research agenda that reflects patient experience and patient engagement.
2. Continue to identify clinical areas where PRO measures can support high-quality, patient-centered care.
3. Refine and prioritize existing measures to establish their clinical practicality via testing and evaluation.
4. Invest in openly accessible tools that providers, payers, and patients can build into health information technology and clinical practice.
5. Create an interoperable, data-sharing mechanism that allows PRO data to be entered, used, and interpreted by every level of a care team (e.g., patient, caregiver, nurse, physician's assistant, post-acute care/long-term care provider).
6. Support workforce development, training, and education to advance best practices for PRO data collection, interpretation, use, and evaluation.
7. Provisionally adopt PRO-based performance measures in pay-for-reporting and accreditation programs.
8. Gradually integrate PRO-based performance measures into provider practice transformation initiatives such as pay-for-performance, then into new payment and delivery models.

Our research highlights many practical ways that patients, payers, providers, and life sciences companies can benefit from experimentation with PRO measures. For example, patients can increase their engagement levels by completing PRO surveys; providers can use PRO measures in clinical practice as a vehicle for driving care improvement and delivering value; payers can experiment with PRO-based performace measures for accountability; and manufacturers can continue to develop instruments for clinical trials.

Despite the upsurge of activity to advance patient-centered measurement, the Dialogue discussions made it clear that our collective healthcare knowledge on these measures is in its early stages, and linkages between PROs and clinical outcomes are still evolving. Participants stressed the importance of a rigorous, step-wise, and nimble PRO development and translation process to accommodate new information and best practices as they emerge. Advancing the use of PRO measures in payment and delivery models will require thoughtful allocation of new and existing resources and infrastructure through the public and private sectors. We expect that these activities can (1) help today's healthcare system overcome key challenges that have impeded our vision for patient-centeredness, (2) enable more effective implementation of PRO measures in new payment and delivery models, and (3) incrementally enhance our understanding and recognition of the true value of care delivered to patients.

This paper, which serves as the output of the 2014 Dialogue Series, offers solutions that can elevate the role of PRO measures in delivering value, improving quality of care, and creating a more patient-centered healthcare system. We hope the impressions captured here provide guidance for individual stakeholder organizations, policymakers, and research entities on how to align quality and performance improvement efforts to reflect patient experience, engagement, and functional outcomes.

About Us

Avalere is a vibrant community of innovative thinkers dedicated to solving the challenges of the healthcare system. We deliver a comprehensive perspective, compelling substance, and creative solutions to help you make better business decisions. We partner with stakeholders from across healthcare to improve health through better data, insights, and strategies. We empower healthcare leaders to take action.

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Introduction

Changing the Way We Pay for and Deliver Healthcare

Faced with constrained budgets and concerns over rising healthcare costs, many policymakers and healthcare stakeholders are showing increasing interest in reforms to curtail spending growth while maintaining or improving the quality of patient care. Many reforms, such as provider pay-for-performance (P4P) programs, bundled payments, accountable care organizations (ACOs), and patient-centered medical homes, seek to create incentives to obtain greater value for each healthcare dollar.[1] As a result, appropriately defining and incentivizing value is of central importance in these programs.

If these new models are implemented poorly—especially if "value" is not defined appropriately—they could place undue emphasis on cost-cutting and create new barriers for patients, providers, and other healthcare stakeholders as they seek innovative, clinically appropriate care.[2] If reforms do not incorporate and incentivize patient-centric attributes of value, they risk conflicting with the movement toward patient and consumer engagement in healthcare.

The Affordable Care Act (ACA), built upon a foundation of public and private sector efforts, contains a range of provisions to support better decision-making by consumers and expands value-based purchasing (VBP) in government and private sector programs. While these provisions differ in design, they share common elements of rewarding providers based on adherence to evidence-based processes and achievement of cost savings, clinical outcomes, and patient experience.[3] The ACA also established the Center for Medicare and Medicaid Innovation (CMMI) and provided it unprecedented funding and authority to test, evaluate, and broadly implement innovative payment and delivery models in Medicare and Medicaid. Since the passage of ACA, multiple stakeholders have focused on the essential role that patients and their families have in achieving a value-based healthcare system (see **Figure 1**).

Figure 1: Select Characteristics to Describe a Highly Engaged Patient [4,5]

While the promise of new VBP programs and payment and delivery models is significant, unanticipated challenges and unintended consequences have also emerged. Reconfiguring financial relationships and shifting monetary risks for the cost of care to providers has raised questions about whether, or to what degree, treatment decisions are affected by these new incentives. As a result, stakeholders increasingly believe that quality measures, when used to assess provider performance (i.e., performance measures[i]), are not only important for improving care but are vital for protecting patient care and advancing patient-centeredness in the context of these new models. These quality and performance measures may capture the degree to which health services are consistent with current clinical standards,[6] including specific care processes (e.g., Discharged on Antithrombotic Therapy[7]) or availability of infrastructure (e.g., Participation in a Systematic Database for Cardiac Surgery[8]), or clinical and patient-reported outcomes (e.g., Depression Remission at Six Months[9]). Quality and performance measures, therefore, must encompass a wide

i. Performance measures are a subset of quality measures against which health professionals are measured; they are used for accountability in P4R, P4P, and VBP programs. Source: American Medical Association Physician Consortium for Performance Improvement. Available at: http://www.amaassn.org/ama1/pub/upload/mm/370/pcpi-evidence-based-statement.pdf

range of clinical conditions and be continuously introduced, modified, and retired in order to reflect clinical best practice. In 2014, the Measure Applications Partnership (MAP), which makes recommendations to the Center for Medicare & Medicaid Services (CMS) regarding measures for inclusion in federal programs, identified significant gap areas, including:

- Clinical safety measures,
- Mental/behavioral health measures,
- Opioid monitoring,
- Cost and value measures,
- Patient-reported outcome data of shared decision-making,
- Advanced care planning, and
- Team-based accountability measures of person- and family-centered care.[10,11]

Different reporting and payment programs often require different quality measures, each with varying configurations and specifications.[12] Each program may also have distinct timelines for updating measures and targets, with limited transparency in how private payers are implementing these tools. This lack of harmonization results in providers spending more time on measurement, which takes away from time that could be spent on care improvement.

Part of the challenge facing policymakers is that value is in the eye of the beholder, and stakeholders prioritize different aspects of value as important in quality measurement. Payers and purchasers may be cost conscious. Patients value care that meets their individual needs (e.g., Can I climb up the stairs in my home? Do I have enough energy to go to work today?). Providers are often caught in between.[13] Despite these different perspectives, stakeholders can all agree that outcomes are a vital component of value.

To date, there has been limited opportunity for patients to engage in the quality improvement environment, especially on measure development and implementation.[14] As Department of Health and Human Services (HHS) quality leaders acknowledged in a *Journal of American Medical Association* paper in June 2013, measuring those areas important and relevant to patients and their families, particularly capturing their experience, is of utmost importance.[15] This can often be achieved through the use of patient-reported outcomes measures (PROMs) and, when used in payment, patient-reported outcomes-based performance measures (PRO-PMs).

Table 1: Defining Patient-Reported Outcome, Patient-Reported Outcomes Measure, and Patient-Reported Outcomes-Base Performance Measure

TERM	DEFINITION
PRO	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 (e.g., depressed mood)[16]
PROM	Tools (e.g., instruments, scales, single-item measures) that enable researchers, clinicians, administrators, patients, or others to assess and value patient-reported health status or experience for physical, mental, and social well-being (e.g., PHQ-9)[17]
PRO-PM	Performance measure based on PROM data aggregated for an entity deemed as accountable for the quality of care or services delivered (e.g., Depression Remission at Six Months for physician practices)[18]

Unlike process measures, which largely capture adherence to standards of recommended care, PROMs attempt to capture whether the treatment, services, and other care strategies actually improved patients' personal health and sense of well-being. And while outcomes measures can evaluate achievement of clinical targets or intermediate outcomes, PRO-PMs can function as surrogates where clinical outcomes cannot be easily quantified. PROMs and PRO-PMs can assess aspects of healthcare delivery that other quality metrics cannot, both at a general health level and at a condition-specific one. PROMs capture aspects of care such as: health-related quality of life; functional status; symptoms and symptom burden (e.g., pain, fatigue); experience with care; behavior change (e.g., smoking, diet, exercise);[19] shared decision-making[20] or other specific outcomes that matter to patients. By providing insight into the impact of illness and disease, data based on PROMs can inform the value of care and treatment from the patient's perspective, particularly for patients with multiple chronic conditions, given the importance of quality of life and patient experience.

In January 2013, the National Quality Forum (NQF), the leading body for endorsement of performance measures, outlined a pathway to translate PROs into NQF-endorsed PRO-PMs.[21] NQF sought to identify and promote an understanding of key methodological issues that need to be addressed in developing and using PRO-PMs for accountability, including how to aggregate patient-level outcomes for measuring performance of the healthcare entity delivering care. NQF is also in the process of reviewing newly submitted measures for endorsement focused on person- and family-centered care.[22] These efforts were key inputs to the 2014 Dialogue Series.

To date, various stakeholders have recognized the importance of PROMs to assess patients' physical, mental, and social well-being, and the role that patients have in defining which PROs are important to assess. Activities in this area have accelerated in the past five years (see **Appendix A**). In the U.S., PROMs have been most widely used for research purposes to monitor aspects of health that rely on patients' reports (rather than diagnostic tests), such as fatigue or functional status, and product developers have sought to incorporate PRO endpoints in pre-market clinical research.[23]

PROs and PROMs for Research Purposes

- The U.S. Food and Drug Administration's (FDA) 2009 Guidance on PROMs has supported their use in clinical trials:[24] Nearly 25 percent of drug labels include PRO-derived data.[25]
- The National Institutes of Health (NIH)'s Patient-Reported Outcomes Measurement Information System (PROMIS) is a database of highly reliable, precise measures of patient-reported health status for physical, mental, and social well-being, which have been used in clinical trials and translational research.[26] The goal of PROMIS is to create more precise measures and to reduce the number of questions needed to make them more feasible for use in clinical practice. Patients have also been involved in developing and validating the PROMIS measures.
- Dartmouth-Hitchcock Medical Center's Spine Center has been collecting outcomes data from its patients since 1997, using the SF-36®, a "short form" survey with 36 general questions used to assess functional health and well-being, and the Oswestry Disability Index, which is used to measure functional disability from low back pain.[27]
- The Patient-Centered Outcomes Research Institute (PCORI) through its funding priorities is focused on developing an action plan for enhancing use of PROs for clinical care, research, and performance monitoring.[28]

Relative to other countries (e.g., U.K., Sweden), PRO-PMs in the U.S. are in the early stages of development and use for accountability purposes. The Agency for Healthcare Research and Quality (AHRQ)'s Consumer Assessment of Healthcare Providers and Systems (CAHPS) surveys are one of the first domestic examples of PROM and PRO-PM use by CMS quality improvement programs, National Committee for Quality Assurance's (NCQA) Healthcare Effectiveness Data Information Set (HEDIS) Measurement Set, most Medicaid programs, select private plans, Department of Defense, and the Office of Personnel Management.[29] CAHPS measures assess how patients experience their care and the providers they encounter. Depending on the particular version of the CAHPS

survey, they describe actual patient experiences around communication, access, health education, shared decision-making, functional status, and customer service.[ii]

In coming years, PROMs and PRO-PMs are expected to play a more central role in assessing performance and differentiating various treatments, in part because of this continuous shift towards patient-centered care and value-based payment approaches. By 2015, healthcare providers participating in the Medicare ACO Program will have to provide evidence of the value they have produced for the patient—as reported through CAHPS surveys.[30] In a parallel effort, HHS' Office of the National Coordinator for Health Information Technology (ONC-HIT) has alluded to incorporating PROMs into future meaningful use standards, which is likely to prompt more widespread use.[31]

CMS is also expected to continue to prioritize PROMs and PRO-PMs in its measure development efforts, as well as via CMMI demonstration funding.[32,33] We include in **Appendix B** other examples of the current use of PROMs and PRO-PMs in the U.S.

A Path Forward

Despite this groundswell of activity, many stakeholders still struggle with how to prioritize the development and implementation of PROMs and PRO-PMs in new payment and delivery models. There are a few fundamental and parallel activities required to optimize the existing efforts and ensure that our healthcare environment has the appropriate infrastructure to advance the use of PRO-PMs:

- Healthcare stakeholders must keep the patient involved in all steps of PROM and PRO-PM development and prioritization, as well as in implementation and use, to ensure that these tools reflect what is important to the patient.
- High impact PROMs should consider the role personal health goals play in their development and implementation (e.g., a patient's fatigue subsides enough that they feel they can go to work).
- High impact PRO-PMs should support public health goals by enabling apples-to-apples benchmarking comparisons and driving quality improvement at a community, state, regional, and national level.

While there is a need for more robust quality measures that optimize clinical outcomes for patients, the focus of this paper is on those measures that are patient-reported in nature as an avenue to begin to address experience, engagement, and other outcomes important to patients. The 2014 Dialogue explored the challenges to the development

ii. Unlike PRO-PMs, however, CAHPS measures population-level experience at a single point in time rather than the degree of improvement for individual patients.

of PROMs and the implementation of PRO-PMs in VBP and new payment and delivery models. This paper offers solutions that can lead to an elevation of their role in delivering value, improving quality of care, and creating a more patient-centered healthcare system.

> *"[We are] having this conversation now so that three years from now we are not asking ourselves: 'What could we have done better to use these programs?'"*
> *—Dialogue participant*

Approach

Avalere surveyed the available literature to identify new imperatives driving patient-centered measurement and payment and delivery reform. We then proposed a framework to address what is necessary for the development, endorsement, implementation, and use of PROMs and PRO-PMs in new models of care. This framework served as the catalyst for discussion at a two-part multi-stakeholder Dialogue series held on May 21, 2014 and July 29, 2014. Participants of the Dialogue included experts representing a wide range of stakeholders: patient groups, payers, HIT vendors, product developers, providers, and the research community. The primary objective of the Dialogue Series was to identify policy solutions to advance the development and use of PROMs and PRO-PMs.

At the first meeting held on May 21, participants discussed the barriers that must be addressed before conceptualizing a vision for increased use of measures that address the various domains of PROs. To further explore some of the more specific challenges to implementation, the group engaged in an interactive exercise to consider how some of the existing tools (PROMs) that are used in PRO-PMs domestically and/or internationally —the Oxford Hip Score, SF-36, Patient Health Questionnaire - 9 (PHQ-9)—could be implemented into three different Medicare programs: a fee-for-service (FFS) system, a pay-for-reporting (P4R) program, and an ACO, respectively.

The second meeting of the two-part series, held on July 29, gave the group of stakeholder experts an opportunity to refine and prioritize policy options that would accelerate the development and adoption of PRO-PMs and address challenges discussed at the first meeting. Through the discussion at both events, PRO-related activities that have occurred to date, and a series of more than 20 one-on-one conversations with co-sponsors, participants, and other key opinion leaders, Avalere refined the original framework to capture the steps required to integrate a PROM or PRO-PM into a payment and delivery program and, ultimately, inform real-world decision-making by healthcare stakeholders.

A Vision for Patient-Centered Measurement

The multi-stakeholder group of experts discussed the importance of PROMs and PRO-PMs in delivering value, improving quality of care, and creating a more patient-centered healthcare system, and identified an ideal vision for the use of PRO-PMs in a healthcare system that is increasingly aligning around value:

> **Continuous quality improvement that engages all stakeholders to incorporate the patient's voice and measures the outcomes that are most important to the patient**

The Dialogue Series found that many different stakeholders will benefit from the advancement of PRO-PMs (see **Table 2**). As PROMs and PRO-PMs become more sophisticated, their proliferation in the healthcare environment can support this patient-centered vision for healthcare. It should also be noted that PROMs and PRO-PMs are only one component of patient-centered care delivery. Many other activities (e.g., improving clinical outcomes, identifying and meeting patients' treatment goals, improving patient experience, communication, empathy from providers) are needed to achieve the vision of consistent delivery of high-quality patient-centered care.

> *"If the healthcare community can begin to realize some of the aspirations around patient experience and patient engagement today, we can expect to see rewards across research and care delivery settings tomorrow."—Dialogue participant*

Table 2: Various Stakeholder Aspirations for the Potential Use of PRO-PMs*

STAKEHOLDER	GOAL
Patient	• Increase engagement in personal health, including treatment options and care plans (i.e., shared decision-making) • Maintain active relationship with provider to collaboratively track progress (both improvements and declines) against personal health goals • Help other population health decision-makers understand what is important to patients
Provider	• Identify PRO-related targets for improvement (e.g., reduce PHQ-9 score by 50 percent at six months[34]) • Identify and implement quality interventions to advance patient care and experience • Benchmark against peers, both in the same system and across other ones • Enhance shared decision-making between the provider and the patient
Payer	• Hold health programs and health insurers accountable for patient experience and outcomes • Ensure that coverage and reimbursement align with patient preference, where appropriate • Benchmark different hospital and health system customers using patient-centered metrics
Caregiver	• Identify opportunities to improve patient experience and care at home • Educate the caregiver and patients they care for on aspects of optimal care
Manufacturer	• Incorporate PROMs in clinical trials for product approval and labeling • Align delivery system incentives with PRO-PMs to encourage patient-centered care and holistic value incentives
Regulator	• Incorporate aspects of health that are important to patients in the evaluation of risks and benefits

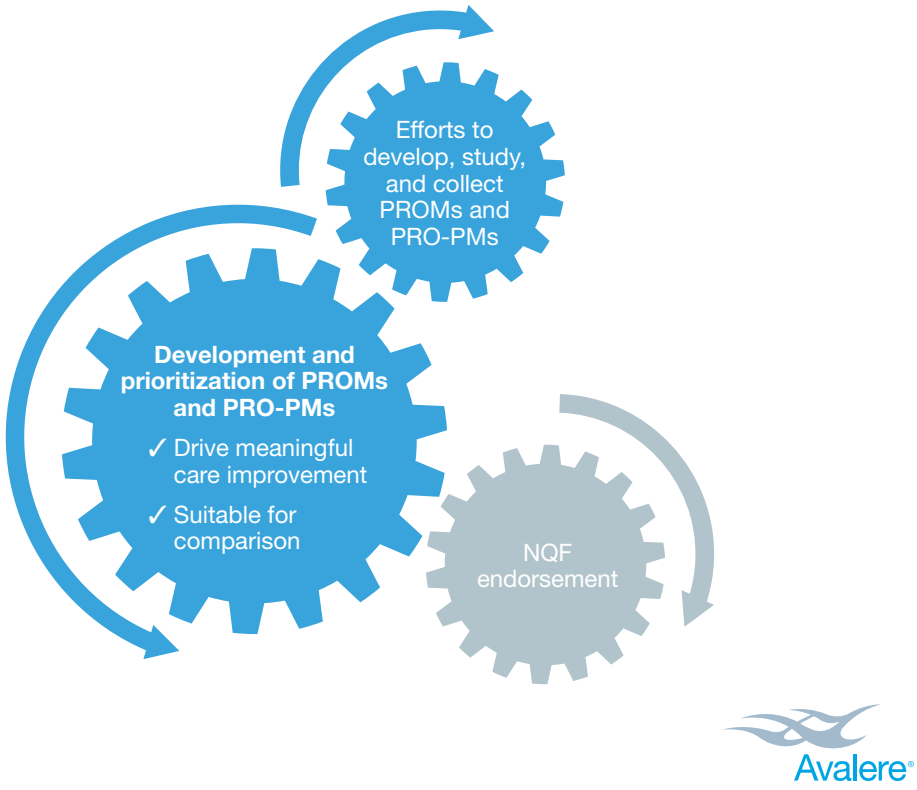
**Not an exhaustive list*

Challenges

Dialogue participants identified a variety of challenges to advancing patient-centered measurement in new payment and delivery models. These related to the development, endorsement, implementation, use, and synchronization of quality and value measures and incentives.

The most significant barrier to advancing integration of PRO-PMs into payment and delivery programs is the lack of existing PROMs and PRO-PMs that can, in fact, be used in these programs in a clinically practical way. Stakeholders continue to question whether the data being collected through existing PROMs is meaningful to both the patient and the provider—and whether this information is of high enough quality to be useful for clinical decision-making and accountability. Despite the wave of activities in this field, PROMs still require significant refinement to be used for quality improvement and benchmarking (see **Figure 2**).[35,iii]

Figure 2: Development and Endorsement of PROMs and PRO-PMs



iii. In their current state, PROMs are not optimally designed to meet the goals of both the patient and the provider. For example, a commonly-used, non-condition-specific PROM (e.g., SF-12), which assesses a patient's health, functional status, and quality of life, may be exactly what a patient needs, whereas condition-specific PROMs (e.g., PHQ-9 for depression) might be a more useful form of measurement for providers assessing disease symptoms rather than general health and well-being.

Our collective healthcare knowledge on PROMs and PRO-PMs is in its early stages, and linkages between PROs and clinical outcomes are still evolving.[iv] In a world where there is still room for improvement in the development and endorsement of quality measures, there is even less infrastructure to support the implementation and use of PROMs and PRO-PMs, and the science of translating these tools into fair measures of publicly reported performance is still in its infancy. One of the clear differences between measures that are more commonly used in today's payment and delivery programs (e.g., process measures) and PRO-PMs is the role that patients play in informing the data that is collected and used to drive quality improvement.

Despite the importance of engaging patients, payment and delivery mechanisms have not historically assessed these types of measures. For example, providers are not able to bill for time spent fielding PRO surveys or utilizing the data for clinical purpose, and it has not always been clear who should be responsible for collecting and aggregating patient input/completed surveys. Some would argue that this should be part of a physician's workflow, whereas others have commented that a nurse and/or physician's assistant may have more of a relationship with the patient to seek information regarding a patient's personal health goals. Outsourcing to an external vendor is another possible avenue for data collection.

Much of the reporting patient and provider burden in this area is attributed to the number of items contained within existing PROMs. With no ideal mix of condition-specific and non-condition-specific PROMs, patients may be inundated with redundant and often lengthy questionnaires. Though some of this patient and provider burden may be reduced with the implementation of a more electronic and automated reporting system (e.g., personal health records [PHRs], patient portals, patient-powered research networks),[v] these efforts take time and resources to implement.[vi]

> *"It is often unclear which providers should administer PRO surveys (e.g., physician, nurse, hospital administrator)."—Dialogue participant*

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iv. Some of the more technical concerns regarding the translation of PROMs into PRO-PMs are currently being considered by NQF, PCORI, and other organizations. Given the subjectivity of PRO data and immutability concerns (i.e., the ability of a provider to affect a PRO score), there are numerous methods-related issues, such as socioeconomic risk adjustment, benchmark setting, mode and timing of administration, and collection mechanisms, to which solutions are currently being explored. Whether measures should be evaluated longitudinally (for a single patient) or adjusted for case mix is also being considered, as are other implementation science concerns that explore the unintended risks and consequences of changing practice. For example, if providers and payers are required to allocate resources to the reporting of PRO-PMs, they may need to deprioritize (move resources away from) another aspect of clinical care; however, we currently have limited knowledge and limited ability to predict what resulting changes will look like or effects on outcomes overall.

v. Measuring and reporting clinical quality measures (CQMs) will help to ensure that our healthcare system is delivering effective, safe, efficient, patient-centered, equitable, and timely care. Through participation in the Medicare and Medicaid Electronic Health Record (EHR) Incentive Programs where clinicians can receive an incentive payment to report, providers are required to submit CQM data through EHR technology. The use of patient portals by ONC-HIT could potentially support this shift to collecting information directly from the patient to drive more patient-centered care.

vi. Federal agencies such as the ONC and various commercial EHR vendors have spearheaded efforts to develop effective, feasible data collection and reporting platforms, yet there still remains a need to streamline the demands on patients, providers, and payers regarding collection of PROMs and PRO-PMs. Because, by definition, PRO-PMs require data (reported by the patient) not traditionally collected through the EHR, the process for developing electronic measures involves an additional step and may include various data reporting mechanisms depending on how the PRO-PM will be used.

Finally, the implementation and use of measures that are reported by the patient require a different methodology and approach for collating and analyzing the data. The process may result in additional steps that diverge from traditional performance measurement workflows and intensify the level of activity and interaction with the patient. It is currently unclear what the role of methods effects is on provider performance scores (e.g., when, where, how, how often a PRO survey is administered) and how to adequately risk adjust for these variables. There has been little standardization and synchronization of data collection and methodology across the continuum of care, despite significant multi-stakeholder investment in research related to PROMs.[vii] Various efforts targeting the development of PROMs, including PRO data collected in clinical trials and PCORI-funded research,[36] FDA's Patient-Focused Drug Development (PFDD),[37] professional society registries, and private initiatives (e.g., PatientsLikeMe® Open Research Exchange [ORE])[38] still seek extended coordination to ensure that efforts are in fact synchronized, complementary, and build off existing touch points with the patient.

Building a Path Forward: Potential Solutions to Assess Value Through PROMs and PRO-PMs

VBP programs and new payment and delivery models are often saturated with extensive quality measurement requirements; however, with rapid and ongoing changes to clinical practice, many of the measures quickly top out or become out-of-date. As this occurs, programs and models will have an opportunity to address gaps and replace outdated or redundant clinical outcomes or process measures with more appropriate measures. In some cases, these measures may be PRO-PMs.

The group emphasized the need for policy solutions to elevate our understanding of the use of PROMs before we can begin to consider PRO-PM use. The group noted that PROMs and PRO-PMs should be developed and used to financially incent providers to perform well on outcomes deemed important by patients and to ensure that patients receive the right care at the right time.

vii. For example, in knee pain, one PROM measures the impact of pain on activity, another measures functional change, and a third measures the impact on daily living. To address some of these disconnects, organizations are beginning to partner on PROM and PRO-PM development and use to ensure better alignment.

Table 3: Summary of Key Challenges and Potential Solutions

	PHASE	CHALLENGE	POTENTIAL SOLUTION
SYNCHRONIZATION **As new PROMs and PRO-PMs are developed, efforts to synchronize data collection and methodology should be consistent across all PRO-related activities**	**Development and Endorsement**	• Questions about whether the data being collected through existing PROMs are meaningful to both the patient and the provider—and whether the data is of high enough quality to be usable for clinical decision-making • PROMs and PRO-PMs not always designed to meet multi-stakeholder goals, given the different settings and stakeholders involved in developing, studying, and collecting PROM data[39] • Inadequate funding to develop non-proprietary PROMs and PRO-PMs, limited investment in workforce training, and few platforms for shared learning • No ideal mix of condition-specific and non-condition-specific PROMs, resulting in burden on patients to complete lengthy, often redundant surveys	• Supplement existing PRO-related efforts by establishing a national measure development research agenda that reflects patient experience and patient engagement • Continue to identify clinical areas where PROMs can support high-quality, patient-centered care • Refine and prioritize existing PROMs and PRO-PMs to establish their clinical practicality via testing and evaluation
	Implementation and Use	• Little alignment within the quality and performance measurement environment, including the myriad accreditation, reporting, performance, VBP, and payment programs (both public and private) • Limited data infrastructure/interoperability for sharing PROM and PRO-PM data, including between different members of a care team • Patient and provider burden, requiring extra time/resources and disrupting normal clinical workflows; this burden may be reduced with the implementation of a more electronic and automated reporting system	• Invest in openly accessible tools to which providers, payers, and patients can build into HIT and clinical practice • Create an interoperable, data-sharing mechanism that allows PROM data to be entered, used, and interpreted by every level of a care team (e.g., patient, caregiver, nurse, physician's assistant, post-acute care/long-term care provider) • Support workforce development, training, and education to advance best practices for PROM data collection, interpretation, use, and evaluation • Provisionally adopt PRO-PMs in pay-for-reporting (P4R) and accreditation programs • Gradually integrate PRO-PMs into provider practice transformation initiatives such as pay-for-performance (P4P), then into new payment and delivery models

Development and Endorsement

Solution: Supplement existing PRO-related efforts by establishing a national measure development research agenda that reflects patient experience and patient engagement

In order to align many of the disparate efforts around PROM and PRO-PM development, there must be a national research agenda to harmonize efforts and align with other aspects of the quality measurement environment. This will allow all current and future PRO-related activity led by industry, quality organizations, research entities, HIT vendors, and other stakeholders to be more valuable and support a consistent set of high-impact, valid PRO-PMs. To support this solution, participants proposed that the HHS could act as an entity that identifies, designates, and/or funds a convener (e.g., Institute of Medicine, NQF, or similar) to set a consensus-based, national research agenda for the development of PRO-PMs around which all interested parties can align. The agenda should build on the National Quality Strategy (NQS), a multi-stakeholder effort at priority setting around the Institute for Healthcare Improvement Triple Aim for improving patient experience, improving the health of populations, and reducing healthcare costs. A national agenda around PROMs and PRO-PMs should consider that the development of PROMs (grounded FDA-recognized PROs) is needed in the short term as a stepping stone for the advancement of PRO-PMs. For example, CMS' "Partnership for Patients: Better Care, Lower Costs" effort has prioritized patient engagement and patients' voices in its Community-based Care Transitions Program and its Quality Improvement Organizations (QIOs) as one of the first steps to executing on the NQS around safer care.[40,41]

Solution: Continue to identify clinical areas where PROMs can support high-quality, patient-centered care

Building on the NQS and measure gaps already identified by MAP and other key quality stakeholders, participants identified the need to define which clinical areas can benefit most robustly from the use of PROMs. Not all therapeutic areas or conditions are ripe for PROM development, but there are those for which functional status, pain, behavior, and other PROs assessed by PROMs are much more relevant (e.g., oncology, rheumatoid arthritis, psoriasis, and other conditions that have a significant impact on patient functional status and/or pain levels). One way to establish this would be via government funding of meta-analyses on the link between PROs and more traditional clinical outcomes, e.g., mortality, readmissions (which drives the link between PRO-PMs and clinical outcomes), as well as the establishment of a coordinating body to support PROM development in a systematic way and to harmonize existing PROM development efforts by industry, academic research organizations, and others. Collecting patient input on the outcomes that are important to them is also a critical step and one that is beginning to be addressed by FDA through PFDD.[42]

Solution: Refine and prioritize existing PROMs and PRO-PMs to establish their clinical practicality via testing and evaluation

Participants recognized that select PROMs and PRO-PMs may be further along in their sophistication. Many of these tools have been thoroughly evaluated in their complete and abbreviated forms (e.g., SF-36 to SF-12®) to reduce respondent burden, and have already demonstrated to providers the clinical value in their use. However, in some cases, there are inconsistencies in the way PROMs are used in clinical workflow, including a lack of standardization in data collection methodology and reporting analytics—which pose challenges to their usability as a PRO-PM.

Beyond methodological issues associated with the development of PROMs,[viii] at least four critical elements need to be resolved in the transition of validated PROMs into practical, valid, and reliable PRO-PMs. First, the role of methods effects on provider performance needs to be resolved. We know from academic research that context matters in survey administration (e.g., time of day, day of week, location, mode), but adjusting for that to allow for comparative performance reporting requires more practical experience with implementation. Second, real-world experience will fill in knowledge gaps regarding the reasonable expectations for the trajectory of change in PROM scores (at an individual level) that will enable PROMs to be used within PRO-PMs (at a population health level). Understanding the relative difficulty of improvement from various baseline levels serves as the PRO-PM equivalent to case-mix adjustment. Third, little experience exists with PROMs and PRO-PMs at the provider level. Using PROMs to assess individual patient response to therapy has different measurement characteristics than using PRO-PMs to measure provider-level performance. It likely will take at least two time periods of change scores in a feasibility study to determine stable and reliable change scores over time. Finally, HIT-enabled tools must accommodate PROMs and PRO-PMs (e.g., single data entry for multiple use, standardized analytics) to ensure their practicality.

This set of research will enable the translation of a PROM into a PRO-PM. NQF's *Pathway for Translating a PRO into NQF-endorsed PRO-PM* may be an important resource for insight into the process for refining existing PROs and PROMs for accountability and comparison/benchmarking.[43]

viii. These tools need to be able to accurately, and reliably show clinically meaningful differences in scores that will facilitate the translation to PRO-PMs. Some of the more technical concerns regarding the translation of PROMs into PRO-PMs are currently being considered by NQF, PCORI, and other organizations. Given the subjectivity of PRO data and immutability concerns (i.e., the ability of a provider to affect a PRO score), there are numerous methods-related issues, such as socioeconomic risk adjustment, benchmark setting, mode and timing of administration, and collection mechanisms, to which solutions are currently being explored. Whether measures should be evaluated longitudinally (for a single patient) or adjusted for case mix is also being considered, as are other implementation science concerns that explore the unintended risks and consequences of changing practice. For example, if providers and payers are required to allocate resources to the reporting of PRO-PMs, they may need to deprioritize (move resources away from) another aspect of clinical care; however, we currently have limited knowledge and limited ability to predict what resulting changes will look like or effects on outcomes overall. PCORI and others are in the early phases of experimenting to gain greater insight into these methods effects.

Implementation and Use

Solution: Invest in openly accessible tools to which providers, payers, and patients can build into HIT and clinical practice

Several PROs and PROMs, including the SF-36,[44] have restrictions on licensing agreements and the proprietary use of the tool. Without open access to PROMs, providers, payers, and patients have been restricted in their ability to experiment with and build PROMs into HIT/daily medical practice. A "low-hanging fruit" for policymakers to consider is either (1) pursue innovative licensing agreements to increase access to existing tools or (2) invest in the development of new tools that would be free of the current intellectual property limitations. Dialogue participants suggested using NIH's PROMIS as a starting point to identify which PROMs can be prioritized for open access,[45] particularly those that address measure gaps identified by the MAP in high-priority clinical areas. To marry these efforts with what is happening today, the group advised that any further development and testing be linked to existing platforms (e.g., PCORnet) to evaluate PROMs for clinical decision-making but with an end goal of their inclusion into payment and delivery models.

Solution: Create an interoperable data-sharing mechanism that allows PROM data to be entered, used, and interpreted by every level of a care team (e.g., patient, caregiver, nurse, physician's assistant, post-acute care/long-term care provider)

As a precursor to translating PROM/PRO-PM data into actual care-improvement interventions, healthcare stakeholders involved in all aspects of the care continuum (i.e., from prevention to follow-up care) need to be able to (1) access the information and (2) understand it. The group agreed that the data would need to fit within existing data infrastructures or systems that will be in place in the near future, such as EHR Meaningful Use Stage II; and that the data must be linked at each entry-point to the data system (e.g., personal health record, patient portal, EHR, claims) in order to tell a complete and comprehensive story about the individual patient. The use of unique patient identifiers could accomplish this; however, its proposal in the policy environment has historically met with resistance due to privacy concerns.[ix,46]

Finally, to support the interpretation of PRO-PM data, Dialogue participants suggested including common language that would make the information easy to understand based on the given audience. For a patient, the translation could leverage communication and dissemination best practices and tools currently being evaluated by PCORI-funded research.[47,48]

ix. Under Section 1173(b), the Department of Health and Human Services (HHS) is required to adopt a standard for a unique health identifier "for each individual, employer, health plan, and health care provider for use in the health care system." However, Congress has held off on enacting this until privacy concerns have been sufficiently addressed. Source: Health Insurance Portability and Accountability Act (HIPAA) of 1996, Pub. L. No. 104-191, §1173(b), 110 Stat. 1936 (codified as amended at 42 U.S.C. 5 1320d-2).

Solution: Support workforce development, training, and education to advance best practices for PROM data collection, interpretation, use, and evaluation

Given the myriad questions and uncertainty about the quality, accuracy, and reliability of PRO data, steps will need to be taken to ensure that data collection methodology and reporting analytics are applied consistently and correctly by providers and payers across all PRO-related activities. As quality measurement continues to be embedded in daily medical practice, Dialogue participants encourage the Association of American Medical Colleges (AAMC), the American Medical Association (AMA), the state medical boards, and other societies to incorporate training on PROM and PRO-PM data collection, interpretation, and use into (1) continuing medical education (CME) and maintenance and certification; and (2) trainings on PRO-PM data collection into healthcare professional trainings for care teams (nurses, medical assistants, etc.).

To advance these goals, participants suggested that PCORI could provide technical assistance to help build capacity for patient and consumer communities to be more engaged in PROM and PRO-PM evaluation. The group also stressed the importance of investing in platforms for shared learning that collate qualitative and quantitative information from demonstrations and other early adopters that can be leveraged real-time by those interested in developing and using PROMs and PRO-PMs. This would be essential in developing the skill sets of the workforce involved in advancing the use of these measures.

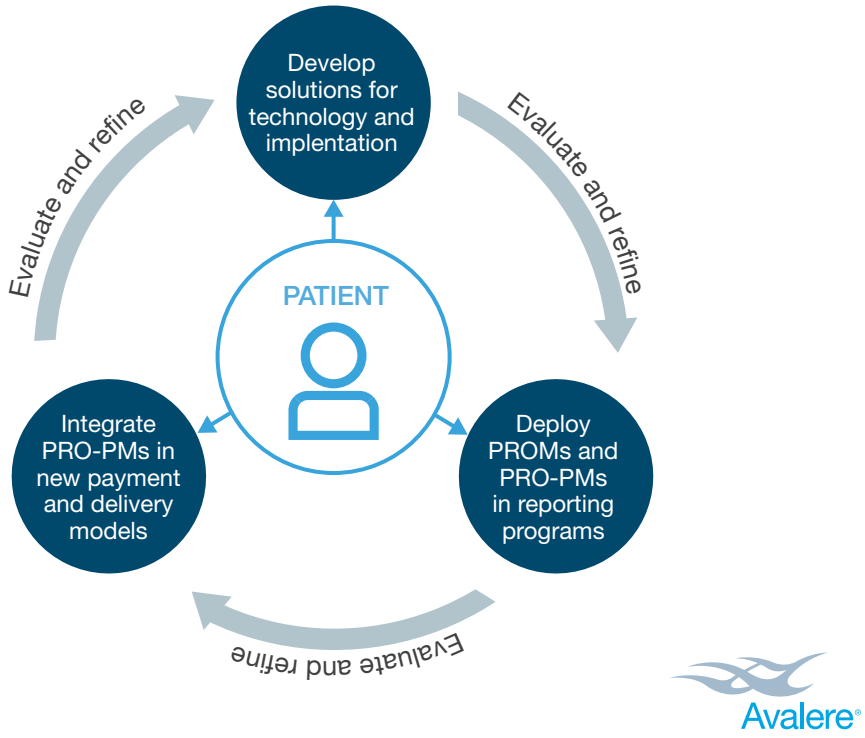
Solution: Provisionally adopt PRO-PMs into P4R and accreditation programs

With limited incentives currently in place to encourage the use of PROMs and PRO-PMs, the group advised that their implementation would need to be stepwise and follow a gradual trajectory to ensure adequate opportunities for continuous learning along the way (see **Figure 3**). The group proposed that NCQA, the Joint Commission, URAC, and other accrediting bodies prioritize the inclusion of PROMs and PRO-PMs in their current accreditation criteria. NCQA has already started to include quality measures related to the patient/caregiver experience as part of its Patient-Centered Medical Home accreditation criteria.[49,50]

CMS and other payers may also consider including established and refined PRO-PMs into existing P4R programs. Participants advised that this occurs with the intent to evaluate how the measure does in the P4R program and whether it is suitable for inclusion in a P4P program (much like the process in place for using measures in the Hospital Inpatient Quality Reporting Program before they are considered for the Hospital VBP program). The inclusion of PRO-PMs in P4R, and other non-financial, quality improvement programs creates an opportunity for the necessary testing and evaluation

of whether a measure is meaningful to the patient, and what operational or implementation challenges may arise when the measures are in place. The group hoped that provisional adoption in these types of programs would result in lessons learned, such as appropriate risk stratification (e.g., socioeconomic status, geographic/zip code-based), benchmark setting, or establishment of a measurement period that would be important to resolve prior to inclusion in payment programs.

Figure 3: Implementation and Use of PROMs and PRO-PMs



Solution: Gradually integrate PRO-PMs into provider practice transformation initiatives such as P4P, then into new payment and delivery models

Once aspects of research and development, technology, and reporting have been addressed, there is an opportunity for PRO-PMs to be tied to payment, while retaining a primary goal of using the PROM itself for care improvement. Given that CMS has already implemented numerous P4P initiatives, efforts such as its Physician Value-Based Payment Modifier program may be an appropriate starting point before PRO-PMs are embedded into ACOs, bundled payments, and other new payment and delivery models. With each further refinement of CMS regulations, the Agency should identify opportunities to integrate PRO-PMs in a harmonized manner across its performance-based payment models.

Synchronization

Solution: As new PROMs and PRO-PMs are developed, efforts to synchronize data collection and methodology should be consistent across all PRO-related activities

Similar to the activities that are being led by the MAP and NIH's PROMIS, efforts to better synchronize the types of PROMs and PRO-PMs that are being developed and used must be aligned. To operationalize this level of synchronization, PROMs and PRO-PMs will need to collect the same level of information to ensure analogous comparisons. For example, a measure captured in the Medicare Advantage Star Ratings program needs to be comparable to a measure captured in a physician setting (regardless of how the individual measure was adapted for that setting of care). PCORI and NIH have already begun to explore how NIH's database could support better synchronization with patient-centered outcomes research (PCOR) through their formation of a PROMIS Task Force in 2013.[51] Achieving some type of synchronization is not necessarily a priority in the early stages of PROM and PRO-PM development and use; however, it must be considered as implementation starts.

Conclusion

Over a decade ago, "patient-centeredness" was embedded into modern notions of quality care by IOM in its report *Crossing the Quality Chasm: A New Health System for the 21st Century*.[52] Today's healthcare dynamic is characterized by this unique shift toward patient-centeredness coupled with the proliferation of payment and delivery changes in the marketplace. But opportunities have been limited thus far for patients to engage in quality improvement.

We are presented with a unique opportunity to respond to the market by **better engaging patients**. A PRO is information that comes directly from the patient about how they feel or function in relation to a health condition and its therapy. As appreciation grows for the value of patient input, many stakeholders are considering what actions are necessary to meet patients' needs. While informing the development/prioritization of and reporting on PROMs is one way for patients to engage, providers and caregivers will need to make that engagement actionable by using the information gleaned from the PROM to influence and update care plans and treatment decisions so that they better align with the patient's personal health goals, needs, and preferences. The use of transparent PROM data may also enable providers to identify strengths and weaknesses

in the care provided, and to benchmark their outcomes against those of their peers (i.e., how successful has a provider been at targeting a patient's health-related goal).

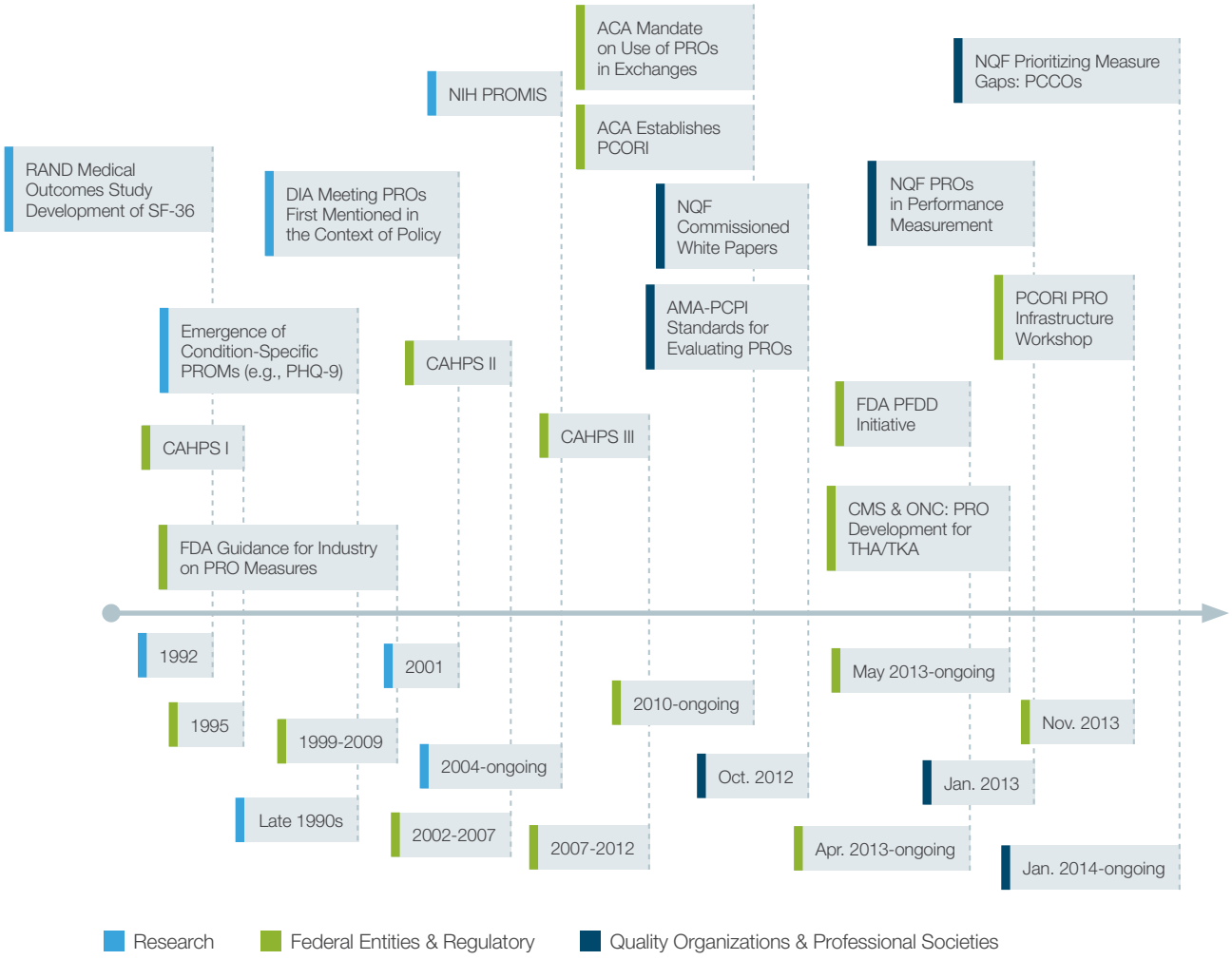
Attention on patient-reported outcomes is aligned with the Triple Aim's focus on improving the quality of care, thereby health of the community, while simultaneously reducing costs. The focus of a PROM resonates with patients since, in most cases, these are things that matter the most: "Can I dance with my granddaughter at her wedding?" or "Will I be able to walk up the stairs?" Engaging patients to better understand what is important to them, how it should be measured, and how it can be used to meet personal and public health goals will be critical as healthcare decision-making increasingly is guided by value-based incentives.

Enacting policy options to advance PRO-PMs in new payment and delivery models, though just one component of the drive to engage patients, will require significant investment both from government as well as the private sector, including the life sciences industry, quality organizations, research entities, HIT vendors, and others. Achieving this vision for patient-centered healthcare will require multi-stakeholder collaboration at each step of the way. We hope the ideas and solutions described in this paper will drive urgency for individual stakeholder organizations and policymakers to align their efforts in ensuring that the evolution and proliferation of PRO-PMs will move us toward an ideal, quality-improved, patient-centered vision of healthcare in the U.S.

Appendix

Appendix A: Summary of Key PRO-Related Activities

Figure 4: "PROs" Are Not a New Concept



ACA: Affordable Care Act; AMA-PCPI: American Medical Association – Physician Consortium for Performance Improvement; CAHPS: Consumer Assessment of Healthcare Providers and Systems; CMS: Centers for Medicare & Medicaid Services; DIA: Drug Information Association; FDA: U.S. Food and Drug Administration; NIH: National Institutes of Health; NQF: National Quality Forum; ONC: Office of the National Coordinator; PCCO: Person Centered Care Outcomes; PCORI: Patient-Centered Outcomes Research Institute; PROMIS: Patient Reported Outcomes Measurement Information System; THA: total hip arthroplasty; TKA: total knee arthroplasty

Table 4 summarizes a list of key activities that have taken place over the past few decades as related to the development of PROMs. Importantly, the 2014 Dialogue Series uniquely focused the conversation on remaining gaps in the development of PRO-PMs and the role that PRO-related quality measures may play in future models of care. Please note, this is not an exhaustive list.

Table 4: Summary of Key PRO-Related Activities

TIMING	ORGANIZATION	PROJECT	RESULT
1992	RAND	Medical Outcomes Study[53]	• Two-year study of patients with chronic conditions, measuring quality of life including physical, mental, and general health • Led to the emergence of the SF-36, a commonly used non-condition-specific PRO instrument
1995	Agency for Healthcare Research and Quality (AHRQ)	Consumer Assessment of Healthcare Providers and Systems (CAHPS) I[54]	• Development of surveys and reports to consumers and other users; standardization of surveys • Adoption of CAHPS I health plan survey by Centers for Medicare & Medicaid Services (CMS), National Committee for Quality Assurance (NCQA), most Medicaid programs, Department of Defense, and U.S. Office of Personnel Management
1995	U.S. Food and Drug Administration (FDA)	Principles for the Promotion of Pharmacoeconomic Promotion (draft)[55]	• Draft for a guidance from FDA that was never released. It was used as a discussion document at a 1995 meeting on the topic • It includes early FDA views on PROs, then referred to as quality of life
1999	Researchers at Columbia University, Regenstrief Institute at Indiana University, Pfizer	Primary Care Evaluation of Mental Disorders (PRIME-MD)[56]	• PHQ-9 developed and becomes frequently used by providers • Condition-specific PROMs begin to proliferate

continued...

TIMING	ORGANIZATION	PROJECT	RESULT
2001	FDA	Presentation by Laurie Burke at Drug Information Association Conference on PROs, New Orleans, LA	• First public use of the term "PRO" at a conference by an FDA presenter
2002–2007	AHRQ	CAHPS II[57]	• Adoption of CAHPS II hospital survey by CMS • National Quality Forum (NQF) endorsement of several CAHPS surveys as measures of patient experience of care
2004 – ongoing	National Institutes of Health (NIH)	Patient Reported Outcomes Measurement Information System (PROMIS)[58]	• System of highly reliable, precise measures of patient-reported health status for physical, mental, and social well-being • Has been used in clinical trials and translational research
2007–2012	AHRQ	CAHPS III[59]	• Use of CAHPS surveys for evaluation of quality improvement effort and reporting purposes
December 2009	FDA	Guidance for Industry, Patient-Reported Outcome Measures: Use in Medical Product Development to Support Labeling Claims[60]	• While Guidance offered principles to industry conducting research and encouraged adoption of scientific standards, the document generated more questions than it answered about the nature of PRO research and the level of needed evidence to make claims.
October 2012	NQF	Commissioned White Papers[61,62]	• Methods paper that addresses issues related to administration, response rates, sensitivity to change and intervention, and selection of PROs for use in accountability performance measures • White paper addresses issues such as methods to aggregate patient-level PRO data in a performance measure and reliability, validity, and risk adjustment of the performance measure

continued...

TIMING	ORGANIZATION	PROJECT	RESULT
October 2012	American Medical Association – Physician Consortium for Performance Improvement (AMA-PCPI)	Standards for Evaluating PRO-PMs	• Hosted a technical expert panel to identify best practices for developing PRO-PMs • Identified five purposes for which PROs can be used in performance measurement • Efforts of the work of AMA-PCPI were included in the NQF report
January 2013	NQF	PROs in Performance Measurement[63]	• Identified "guiding principles" to select PROMs in the context of performance measurement • Presented pathway from PRO through PROM and PRO-PM to NQF endorsement
April 2013 – ongoing	FDA	Patient-Focused Drug Development (PFDD)[64]	• Series of meetings focused on high-burden diseases to obtain patient perspectives on the appropriate framework for considering risk and benefit of currently available treatments as well as new products under development
May 2013 – ongoing	CMS	PROs Following Elective Total Hip and/or Total Knee Arthroplasty (THA/TKA)[65]	• Will develop 1-2 patient-reported outcome-based performance measures following total hip and/or knee arthroplasty (THA/TKA, either a single combined or two procedure-specific measure) that can be used for hospital-level performance measurement
May 2013 – ongoing	Office of the National Coordinator (ONC)	PROs Following Elective Total Hip and/or Total Knee Arthroplasty (THA/TKA)[66]	• Will develop 2 patient-reported electronic clinical quality performance measures following THA and TKA, respectively, that can be used for eligible professional (e.g., physician)-level performance measurement in CMS' Electronic Health Record (EHR) Incentive Program
November 2013	Patient-Centered Outcomes Research Institute (PCORI)	PROs Infrastructure Workshop;[67] PCORI also awards grants to research institutions seeking to study PROs	• Discussed strategies for increasing the use of PROs in EHRs • Focused on developing an action plan for enhancing use of PROs for clinical care, research, and performance monitoring
January 2014 – ongoing	NQF	Prioritizing Measure Gaps: Person-Centered Care and Outcomes[68]	• Build's on NQF's PROs in Performance Measurement project and the national implementation of PRO-PMs in Britain's National Health System to advance performance measurement in this area

Appendix B: Case Studies on Early Adopters of PROMs and PRO-PMs

Minnesota Community Measurement: Capturing PROMs that Matter to Patients

Minnesota Community Measurement (MNCM) is a not-for-profit organization that engages with a variety of statewide stakeholders in order to create and refine measures as well as collect and report data for use in healthcare improvement.[69] The organization has been reporting on healthcare performance since 2003. In 2006, MNCM and the Institute for Clinical Systems Improvement (ICSI) began to experiment with the use of PROMs in preparation for the implementation of the Depression Improvement Across Minnesota—Offering a New Direction (DIAMOND) Initiative, a depression care model innovation for the state of Minnesota.[70]

MNCM provides important insights into the process of population-relevant PROM selection. A convener for measure selection, MNCM has approached the selection of PROMs through an assessment of community need and related initiatives for collaboration. MNCM identified depression as a community need in the mid 2000s along with their collaborative partner Institute for ICSI. In 2008, ICSI launched the first wave of the DIAMOND Initiative, which is focused on reaching out to patients newly diagnosed with depression. In alignment with this initiative, MNCM began to use the PHQ-9 for depression in 2008 across the state. MNCM also assessed a need for chronic asthma control improvement in Minnesota. Previously the group had measured the presence of an asthma controller medication and action plan only. In order to improve asthma care for the state they began using the Asthma Control Test in 2010.

Despite widespread agreement around the need to address depression, providers were not originally aligned around the PHQ-9 as the optimal tool for quality improvement. Some providers proposed other depression inventories—for example, the obstetrics community was interested in a post-partum measure. However, MNCM ultimately selected the PHQ-9 for the ease of having one measurement and data transparency for the condition. Once selected, some providers experienced challenges in integrating the PHQ-9 into clinical workflow, including coding in patient charts and provider confusion regarding actionability of the measure. To address integration barriers, MNCM trained providers on the implications of PROMs and how to engage with patients on utilizing measures to create a course of action.

In January 2011, the "Depression: Utilization of the PHQ-9 Screening Tool" was endorsed by the National Quality Forum, giving it more of an opportunity to be adopted into new payment and delivery programs for widespread use. As of 2014, both (PHQ-9 and Asthma Control Test) PROMs are engaging patients and providers in shared decision-making and facilitating benchmarking comparisons (on a clinic and system level) to encourage continuous quality improvement. MNCM can provide a valuable approach

to other stakeholders seeking to adopt PROMs—in particular, MNCM provides lessons learned regarding the process of PROM selection based on identified community needs. Though this approach is taking place at a regional level, the methodologies employed could lay the groundwork for wider adoption across states.

Blue Cross Blue Shield Alternative Quality Contract: A Patient-Centered Vision of Care in the Private Payer Space

The Blue Cross Blue Shield (BCBS) of Massachusetts Alternative Quality Contract (AQC) is a population-based global budget contract with significant incentives tied to performance on a broad set of quality measures. The AQC attempts to reduce medical spending while improving healthcare quality by holding provider organizations —including multispecialty groups, independent practice associations (IPAs), and physician-hospital organizations—accountable for providing care within a global budget and remain eligible to receive performance-based incentive payments. Payments depend on meeting performance targets on specified, nationally accepted process, outcome, and patient-experience measures. Performance targets for each measure include a range that represents good to exceptional care, defined in absolute (not relative) terms. This structure encourages sharing of best practices among provider groups and motivates ongoing effort for improvement across the performance continuum over the course of the multi-year contracts.[71] This model was developed in 2007 as coverage expansion took place in Massachusetts and officially launched in January of 2009. Provider participation is voluntary; as of 2014, approximately 89 percent of specialists and 85 percent of primary care providers in the BCBS-MA network are contracted through the AQC.

In 2013, BCBS-MA worked in collaboration with AQC providers to identify priority areas in which to test implementation of PROMs. The group identified two priority clinical areas for voluntary PROMs implementation: depression and joint pain (hip/knee replacement or early diagnosis of joint pain). These were selected because the plan and providers anticipated the opportunity to observe significant change in functional status or well-being measures over a relatively brief period of time; additionally, these measures engaged both specialists and primary care providers. Thirteen of 16 provider groups within the BCBS-MA market area elected to implement PROMs in their practices; 10 decided to focus on depression and three on joint pain.[72]

Groups choosing to participate in the AQC PROMs collaborative receive payment for implementing and reporting the data. BCBS-MA is using the information for empirical analyses that are needed to evaluate key psychometric properties of the measures when they are implemented in real-world practice (as opposed to clinical trials). This initial

phase in which practices are rewarded for integrating PROMs into clinical workflows and patient care is conceptualized by BCBS-MA as Phase I of a three-phase process that can ultimately lead to accountability for the results achieved on the measures. In Phase II, BCBS-MA envisions the use of PROMs data to inform shared decision-making, wherein providers will have an empirical basis for advising patients about the likely functional health outcomes that they can expect with any of various treatment approaches. Phase III represents the points at which providers would be paid for the results achieved on PROMs—that is, improvements in measures of functional status, pain, or well-being achieved through patient care. BCBS-MA notes that there is deep empirical work required in order to evaluate how and whether this type of accountability for outcomes on PROMs will be possible and appropriate. However, the plan views the initial two phases of work as providing significant value and contributing importantly to advancing patient-centered outcomes-oriented care.

Figure 5: Pathway to Accountability for PROMs

As a result of the voluntary nature of this model, the collaborative decision-making process used in selection of PROMs, and the phased structure of this approach, the introduction of patient-focused measures into the AQC has received positive buy-in from clinicians; providers have reported that knowledge of aggregate quality scores has contributed to improved care. Though the AQC is still in its early phases of adoption, the approach put forward toward capturing PROMs can provide valuable lessons to other private payers.

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The views reflected in this paper are intended to encompass the multi-stakeholder input captured at the 2014 Dialogue Series, rather than the views of any individual or organization.

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