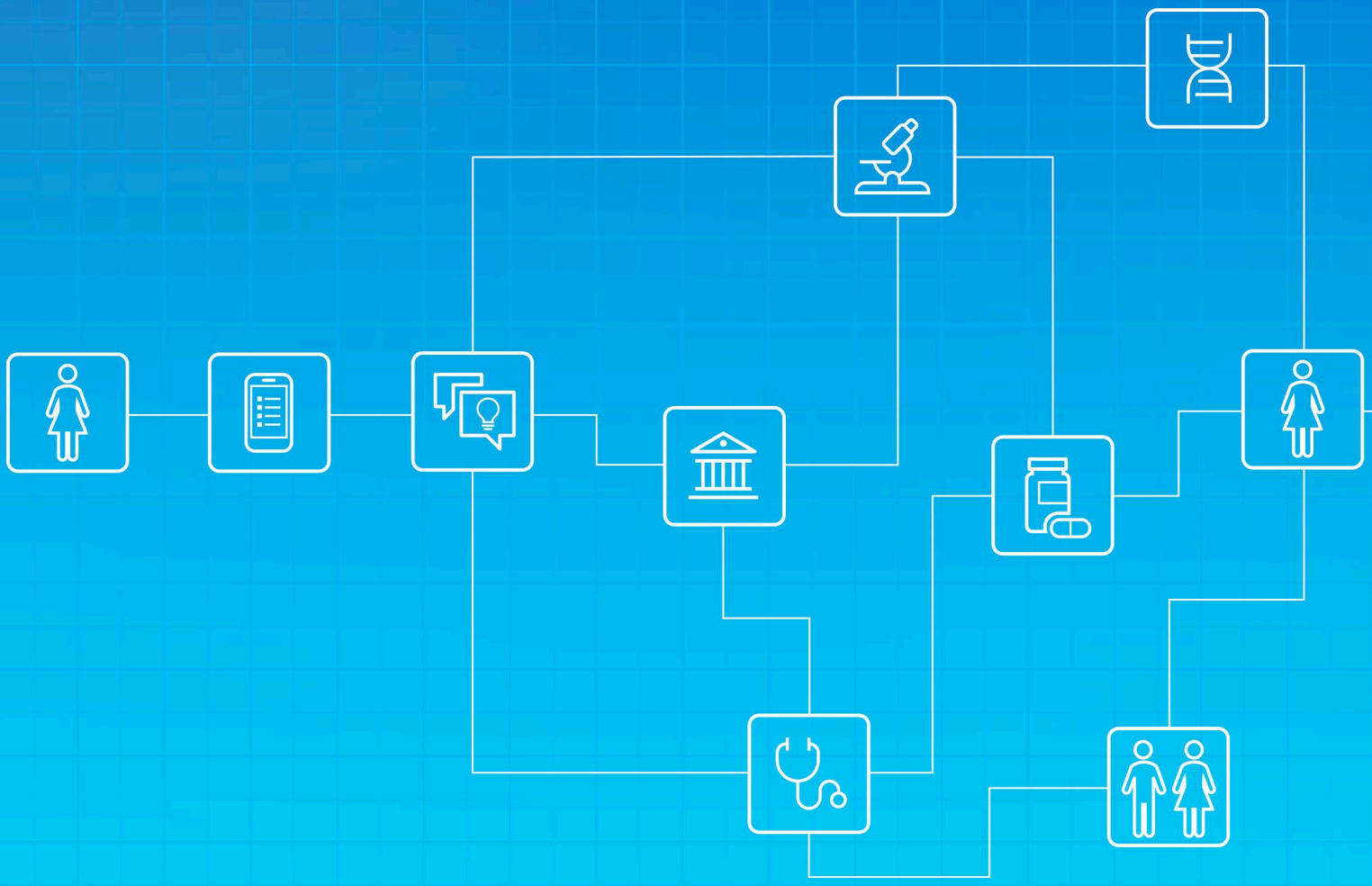
IMPROVING PATIENT-REPORTED MEASURES IN ONCOLOGY



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Acknowledgments
The authors acknowledge the important contributions of Donna Dugan, Russ Montgomery, David Blaisdell, and Sarah Sampsel at Discern Health; Taruja Karmarkar, Emily Gerston, and Andrea Hofelich at NPC; and graphic designer Sooki Moon. The authors are grateful for the insights provided by the interviewees and multistakeholder roundtable participants listed individually in Appendix IV.

Discern Health
Discern Health is a consulting firm that works with clients across the private and public sectors to improve health and health care. Our focus is enhancing the value of health care services through quality-based payment and delivery models. These models align performance with incentives by rewarding doctors, hospitals, suppliers, and patients for working together to improve health outcomes and health care processes while lowering total costs. Discern has been involved in value-based purchasing projects since its founding in 2004. Discern's clients include a range of organizations – pharmaceutical companies, providers, payers, policymakers, purchasers, and national thought leadership organizations – that are driving the agenda for change in health care. More information on Discern is available at www.discernhealth.com.

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ACRONYM GLOSSARY

Acronym	Full Name
ACO	Accountable care organization
AHRQ	Agency for Healthcare Research and Quality
CAHPS®	Consumer Assessment of Healthcare Providers and Systems
CMS	Centers for Medicare and Medicaid Services
EHR	Electronic health record
EORTC	European Organisation for Research and Treatment of Cancer
EPIC	Expanded Prostate Cancer Index Composite
FACIT	Functional Assessment of Chronic Illness Therapy
FACT	Functional Assessment of Cancer Therapy
HIT	Health information technology
IT	Information technology
MACRA	Medicare Access and CHIP Reauthorization Act of 2015
MDASI	MD Anderson Symptom Inventory
MIPS	Merit-based Incentive Payment System
MSSP	Medicare Shared Savings Program
NPC	National Pharmaceutical Council
NQF	National Quality Forum
NQMC	National Quality Measures Clearinghouse
OCM	Oncology Care Model
PCHQR	PPS-Exempt Cancer Hospital Quality Reporting
PCPI	Physician Consortium for Performance Improvement
PHQ-9	Patient Health Questionnaire-9
PhRMA	Pharmaceutical Research and Manufacturers of America

Acronym	Full Name
PPS	Prospective Payment System
PRM	Patient-reported measure
PRO	Patient-reported outcome
PRO-CTCAE™	Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events
PROM	Patient-reported outcome measure
PROMIS	Patient-Reported Outcomes Measurement Information System
PRO-PM	Patient-reported outcome performance measure
PR-PM	Patient-reported performance measure
QCDR	Qualified Clinical Data Registry
QOPI®	The Quality Oncology Practice Initiative
QPP	Quality Payment Program
VBP	Value-based payment

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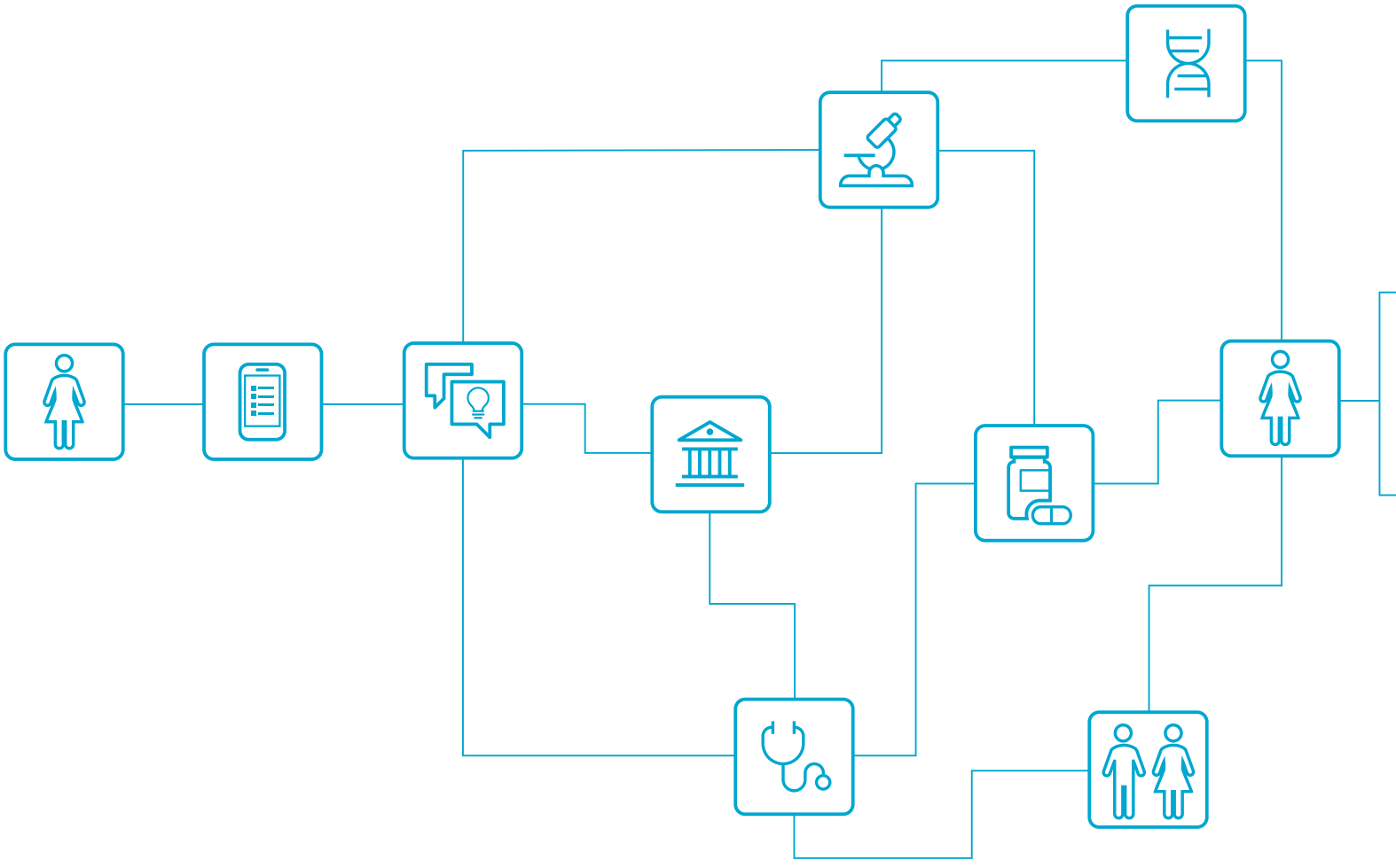


EXECUTIVE SUMMARY

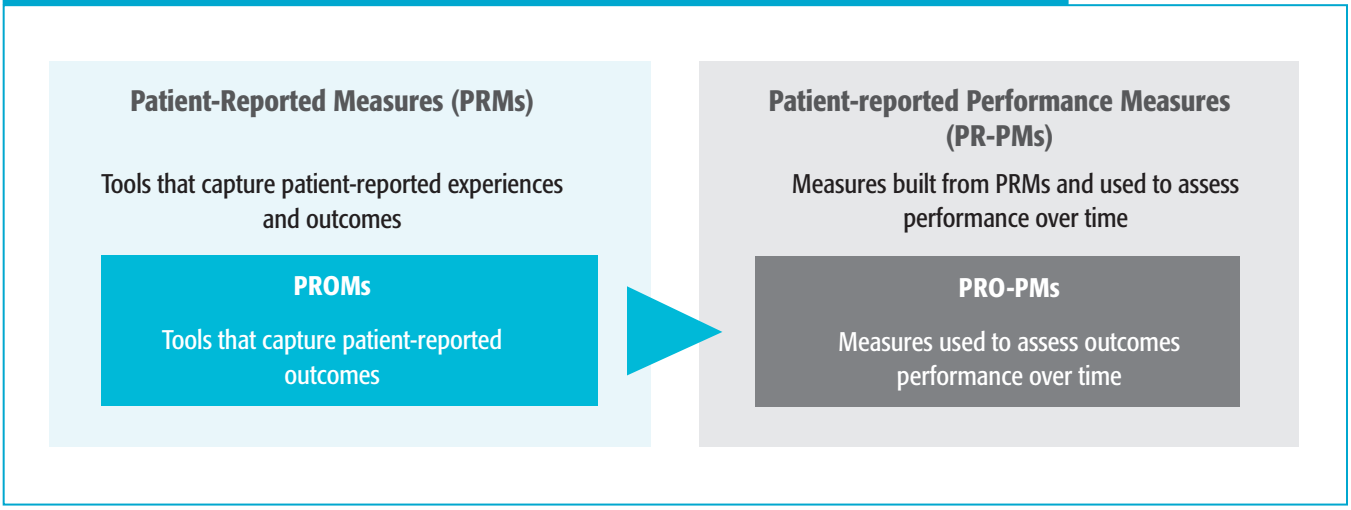
Patient-reported Measures in Accountable Care

The shift to increased health care provider accountability and value-based payment (VBP) has been accompanied by a need for quality and cost measures that are meaningful to patients. The Centers for Medicare and Medicaid Services (CMS), the National Quality Forum (NQF), and other priority-setters in performance measurement have emphasized the necessity of including the patient perspective in definitions of value and the measures used to assess it. NQF asserts that patients are an authoritative source of information not only on their experiences of care, but also on their health care outcomes.[1] The CMS "Meaningful Measures" framework includes both "Patient's Experience of Care" and "Patient Reported Functional Outcomes" as areas intended to meet the quality priority to "Strengthen Person and Family Engagement as Partners in Their Care."[2]

To bring patient, family, and caregiver voices into health care delivery and evaluation, these stakeholders advocate the use of patient-reported outcome measures (PROMs) and patient-reported outcome performance measures (PRO-PMs). In this report, we use the terms patient-reported measures (PRMs) and patient-reported performance measures (PR-PMs) to emphasize that the patient voice can be expressed in measures beyond those specific to outcomes. Figure ES-1 presents the relationships among these concepts.

PRMs are tools, such as surveys, that capture patients' voices related to their care experiences and outcomes. PR-PMs translate PRM responses into metrics that may be used to assess clinician-, organizational-, system-, and population-level performance; compare entities; and measure changes over time. Patient feedback may be incorporated into accountability programs, such as VBP models, and tied to financial incentives or penalties based on the collection of PRMs or the reporting or performance of PR-PMs.

Figure ES-1: The Relationships Among PRMs, PROMs, PR-PMs, and PRO-PMs



Exploring Challenges in Implementing Oncology-related PRMs

Oncology is a complex branch of science covering many disease states and patient types. The importance of including the patient voice in improvement and accountability efforts is sometimes overshadowed by the difficulties in developing methodologically sound PRMs and implementing meaningful PR-PMs in accountability programs. These challenges are particularly pronounced for the diverse oncology population and have led to gaps in the availability and use of PR-PMs. Exploring the barriers to PR-PM creation and implementation and offering possible solutions are foundational steps on the path to incorporating patient perspectives into accountable care for oncology.

With funding from the National Pharmaceutical Council (NPC), Discern Health sought to better understand the current state of patient-reported measurement in oncology and chart a path to a more patient-centered state by:

1. developing an organizing framework and performing an environmental scan and gap analysis of existing PRMs and PR-PMs, including their implementation in accountability programs;
2. interviewing experts and stakeholders in oncology, VBP, and quality measurement;
3. conducting a survey of roundtable participants on PRMs and PR-PMs in oncology; and
4. facilitating a multistakeholder roundtable to explore challenges and opportunities.

This report explores the landscape of available PRMs and PR-PMs, discusses how they are currently used, and offers recommendations for filling gaps in measurement and removing barriers to implementation.

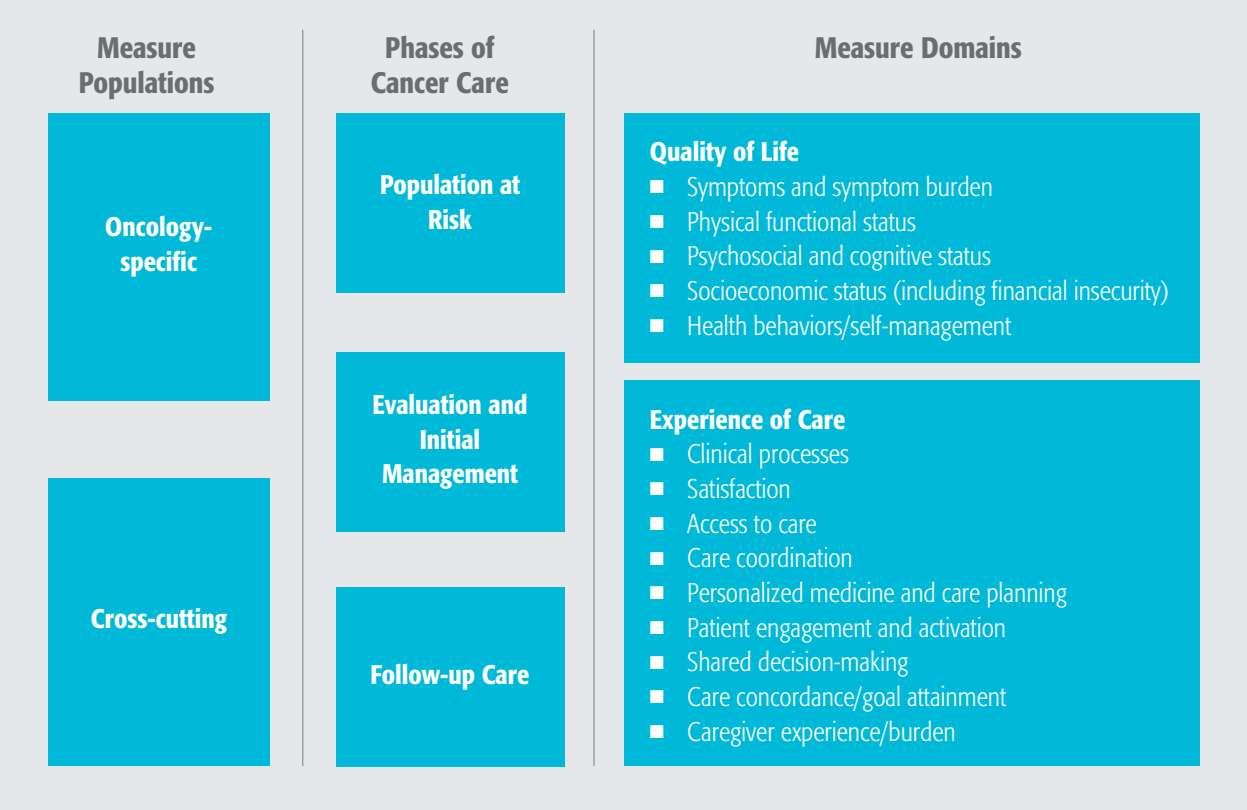
Key Findings

Framework and Landscape Scan

Discern developed a framework for evaluating the current environment of PRMs and PR-PMs (Figure ES-2). The framework entails: 1) identifying oncology-specific and cross-cutting[i] PRMs and PR-PMs that may be applicable to an oncology population, 2) assessing the PRMs' and PR-PMs' applicability to each of three phases of care, and 3) classifying each PRM and PR-PM into one or more of 14 measure domains in quality of life and experience of care categories. We used this framework to describe the current landscape of available PRMs and PR-PMs and to identify gaps in measurement, primarily related to the use of PR-PMs in accountability programs.

i The Centers for Medicare and Medicaid Services (CMS) has defined cross-cutting measures as measures that are "broadly applicable across multiple providers and specialties." In this project, "cross-cutting" refers to measures that were not oncology-specific but could include the oncology population and be applied to at least one of the phases of cancer care.

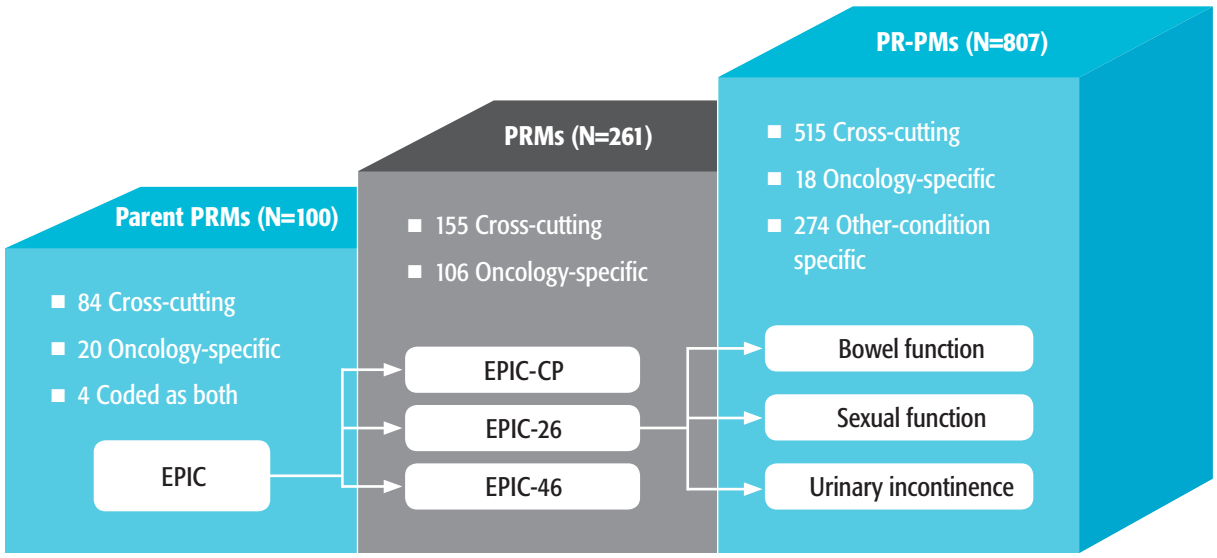
Figure ES-2: Framework for Evaluating Availability of PRMs and PR-PMs in Oncology



The landscape scan and gap analysis identified over 800 PR-PMs from several sources, including oncology-specific measures, cross-cutting measures, and measures specific to other conditions. We found associated PRMs for oncology-specific PR-PMs and cross-cutting PR-PMs relevant to an oncology population. Multiple PR-PMs were often based on different items within a single PRM, and some PR-PMs did not specify which PRM would be used. We also identified oncology-specific PRMs that were not yet associated with PR-PMs. Because many individual PRMs are derived from the same basic PRM or are part of a series, we introduce the term "parent PRM" to describe related PRMs.

Figure ES-3 illustrates the number of PR-PMs and PRMs identified, using the Expanded Prostate Cancer Index Composite (EPIC) as an example of a specific parent PRM with associated PRMs and PR-PMs. EPIC is classified as a parent PRM of the EPIC-CP, EPIC-26, and EPIC-46 PRM instruments. Each of these instruments has associated PR-PMs. For example, the survey questions from the EPIC-26 support PR-PMs measuring the impact of treatment on patients' bowel function, sexual function, and urinary incontinence, respectively, when comparing a baseline PRM given at the beginning of treatment to the same PRM administered during follow-up.

Figure ES-3: Summary of PRMs and PR-PMs



Discern's analysis of the identified PRMs and PR-PMs yielded the following results:

- Cancer-specific PR-PMs are associated with different measure domains than cross-cutting PR-PMs. For example, when compared with cross-cutting PR-PMs, a higher percentage of oncology-specific PR-PMs are related to quality of life and fewer capture patient experience of clinical care.
- Similar patterns emerged in the domains covered by cross-cutting and oncology-specific PRMs as compared to PR-PMs. One exception is that many oncology-specific PRMs capture psychosocial and emotional factors, which is rare in PR-PMs.
- Gaps in available PRMs and PR-PMs for oncology are apparent in several domains: goal attainment and care concordance, socioeconomic status, personalized medicine and care planning, caregiver burden, and the follow-up care phase (specifically related to survivorship).
- Seven PR-PMs have been implemented in accountability programs relevant to oncologists, including the Prospective Payment System (PPS)-Exempt Cancer Hospital Quality Reporting (PCHQR) program, the Oncology Care Model (OCM), the Merit-based Incentive Payment System (MIPS), and the Medicare Shared Savings Program (MSSP).

Stakeholder and Expert Input

The landscape scan informed the stakeholder and expert interview questions, and both provided content included in the pre-meeting survey. All three of these inputs contributed to a roundtable meeting that allowed participants to discuss the uses of PR-PMs, implementation challenges, and gaps in measurement focused on the use of PR-PMs in VBP models.

Key takeaways from the stakeholder and expert input were as follows:

- A modified version of the layered measurement approach, introduced in the Discern and NPC white paper *Accountable Care Measures for High-Cost Specialty Care and Innovative Treatment*,[3] is useful for describing three applications of PRMs and PR-PMs in oncology:
  - PRMs may be used for **clinical care** at the provider level.
  - PRMs and PR-PMs may be used for **quality improvement** at the provider and system levels.
  - PR-PMs may be used for **accountability** at the provider, system, and population levels.
- While some PRMs and PR-PMs, such as those related to symptoms and symptom burden, can be applied to all three applications, some are less versatile.
- Roundtable participants specifically noted that PR-PMs used in accountability programs should be held to a high standard for validity and reliability because of their potential to influence provider behavior and payment.
- Barriers to implementing PR-PMs in accountability programs for oncology include methodological challenges, lack of appropriate resources for providers, insufficient incentives, patient burden and survey fatigue, and a lack of meaningfulness in PRMs and PR-PMs. These barriers have many nuances, contributing factors, and potential solutions, as described in this report.
- High-priority domains for PR-PM implementation in value-based payment programs include care coordination, access to care, and symptoms and symptom burden.
- Specific high-priority PR-PM concepts to develop for inclusion in accountability programs are related to:
  - physical symptoms and symptom burden,
  - psychosocial status,
  - care concordance with patient goals and values,
  - access to care, and
  - socioeconomic status (specifically financial toxicity).

Recommendations for Improving Patient-reported Measures in Oncology

The findings in this report suggest a vision for the future of oncology accountable care in which payment is tied to PR-PMs that are meaningful to patients and reliably representative of provider performance. Core tenets of this vision are:

- Patients and caregivers are involved in decisions about quality measure development and use.
- PRMs and PR-PMs represent the range of care phases and measure domains meaningful to oncology patients.
- Patient and provider burden is minimal.
- Providers have the resources needed to implement and use PRMs and PR-PMs.

To achieve this vision, we recommend the strategies and action steps for policymakers and measure developers in Table ES-1.

Table ES-1: Recommended Strategies and Action Steps

Strategy 1	Action Steps
Involve patients and caregivers throughout all aspects of the measures life cycle to ensure measures capture value	**Policymakers:** ■ Offer funding to support patient engagement in the development and evaluation of PR-PMs ■ Require patient involvement in the development process for measures used in programs ■ Involve patients and caregivers in program measure set evaluation
	Measure Developers: ■ Design patient-centered forums for patient engagement in measure prioritization ■ Seek a diversity of patient and caregiver perspectives at each stage of the measure development process ■ Solicit feedback on meaningfulness and unintended consequences after implementation

Strategy 2	Action Steps
Fill care phase and domain gaps in PRMs and PR-PMs	**Policymakers:** ■ Set measure development priorities related to filling gaps by offering grants ■ List gap areas among the priorities described in the CMS Meaningful Measures initiative and other projects ■ Include PR-PMs for care coordination, symptoms and symptom burden, and access to care in updated program measure sets (such as the OCM) ■ Serve as the steward for PR-PMs that fill gap areas and use the PR-PMs in programs
	Measure Developers: ■ Create PR-PMs to fill gaps, sourcing them from existing PRMs where possible ■ Pursue PRMs and PR-PMs that are broadly useful for clinical care, quality improvement, and accountability ■ Develop specific PR-PM concepts prioritized by roundtable participants for use in VBP programs: - Symptoms interfered with daily activities - Symptoms and functioning were collected and conveyed to providers - Provider assessed patients for emotional or social status or concerns and offered referral to treatment - Patient goals and values were considered across the cancer treatment process

Strategy 3	Action Steps
Address methodological challenges	**Policymakers:** ■ Ensure that PR-PMs selected for VBP programs meet high standards of scientific rigor ■ Address small-numbers bias by choosing cross-cutting PR-PMs, measuring at the group or system level, or combining data from multiple years ■ Continue to fund the development and evaluation of meaningful, methodologically sound, and "fit for purpose" PRMs and PR-PMs
	Measure Developers: ■ Allow the intended use(s) of each PRM or PR-PM to inform the development of measure specifications ■ Apply risk adjustment to address the clinical and sociodemographic complexity of cancer patients

Strategy 4	Action Steps
Reduce provider and patient burden by standardizing and aligning use of PRMs and PR-PMs	**Policymakers:** ■ To align measure use across programs, choose standard PR-PMs and/or PR-PMs built from standard PRMs ■ Select PR-PMs based on PRMs that are useful in clinical care in addition to accountability
	Measure Developers: ■ Build PR-PMs from existing PRMs where possible ■ Create PRMs that are adaptable, fit for multiple purposes, and capture a variety of patient needs, goals, and preferences ■ Eliminate any PRM questions that are not useful or meaningful; use technology to automatically skip irrelevant questions

Strategy 5	Action Steps
Support providers in PRM and PR-PM implementation	**Policymakers:** ■ Offer training, grants, and additional incentives to help fund initial implementation of PR-PMs in VBP programs ■ Subsidize resources needed to administer PRMs, such as improved technology or a free standardized PRM ■ Create incentives for electronic health record (EHR) vendors to incorporate standardized PRMs ■ Adopt stepwise approach to program implementation: support providers in implementing PRMs, set realistic expectations about initial performance, collect and evaluate data, improve PR-PMs over time, and give providers time and information to learn and improve before paying for performance
	Measure Developers: ■ Provide implementation guidance to CMS, health plans, and providers for using their measures

Conclusions

Policymakers, measure developers, and other stakeholders are working to increase the use of PR-PMs in accountability programs for oncology while minimizing the likelihood of potential unintended consequences. For example, implementing inappropriate or poorly designed measures may incentivize behaviors and outcomes that are not meaningful or do not accurately reflect quality of care, and implementing too many measures could create patient and provider burden.

This paper outlines the landscape of PRMs and PR-PMs along with specific barriers to implementing PR-PMs in accountability programs. To address these barriers, policymakers and measure developers should involve patients throughout the phases of measure development and program design, build on existing PRMs to standardize instruments and fill critical gaps in measurement, offer appropriate incentives for implementation, and ensure development methodology considers the complexity and variety of cancer patients and treatment.

These recommendations will help ensure that VBP programs incorporate PR-PMs that reflect patient priorities and meaningfully measure quality of care.

INTRODUCTION

As the health care payment system continues to shift from volume-driven to value-driven models, the concept of patient-centered care has been emphasized by stakeholders seeking to define "value." Patient-reported outcomes (PROs) are an important component of ensuring care is patient-centered. The National Quality Forum (NQF) defines a PRO as "any report of the status of a patient's (or person's) health condition, health behavior, or experience with health care that comes directly from the patient, without interpretation of the patient's response by a clinician or anyone else."[4] PROs are collected through patient-reported outcome measures (PROMs), which are tools, such as surveys, that capture patient responses regarding these outcomes.[5] PRO performance measures (PRO-PMs) are quality measures that assess performance on a given outcome over time.[6]

PROs are particularly important for oncology, as cancer diagnosis and treatment can create significant psychological distress, physical functioning deficits, and quality of life burdens for patients and their families. Research indicates that using PROMs is associated with improved symptom control, increased supportive care measures, and high patient satisfaction.[7] For patients receiving chemotherapy for advanced cancer, systematic monitoring of patients' symptoms using electronic PROMs is related to improved clinician awareness of symptoms, better symptom management, fewer visits to the emergency room, better quality of life, and higher overall survival.[8,9]

As the options for treatment become more personalized through emerging targeted therapies, patient participation in care planning and understanding treatment options and objectives becomes even more important. Moreover, as payment shifts to value-based arrangements, concerns about controlling the costs of specialty oncology drugs must be countered by incorporating effective and meaningful PRO-PMs to ensure that patients' goals are considered. Likewise, PRO-PMs may be used throughout the product life cycle to inform development, testing, approval, and ongoing assessment of oncology treatments.[10,11]

In March 2018, Discern Health received funding from the National Pharmaceutical Council (NPC) to assess the current landscape of PROMs and PRO-PMs in oncology, building on two prior Discern/NPC projects: *Improving Oncology Measurement in Accountable Care* and *Improving Quality Measures for Accountable Care Systems*. The current project entailed reviewing measures and measure gaps in critical domains and identifying strategies for developing and/or enhancing PROMs and PRO-PMs for use in accountable care programs. The project consisted of four major phases:

1. PROM and PRO-PM Landscape Assessment and Gap Analysis
2. Subject Matter Expert Interviews
3. Multistakeholder Survey
4. Multistakeholder Roundtable

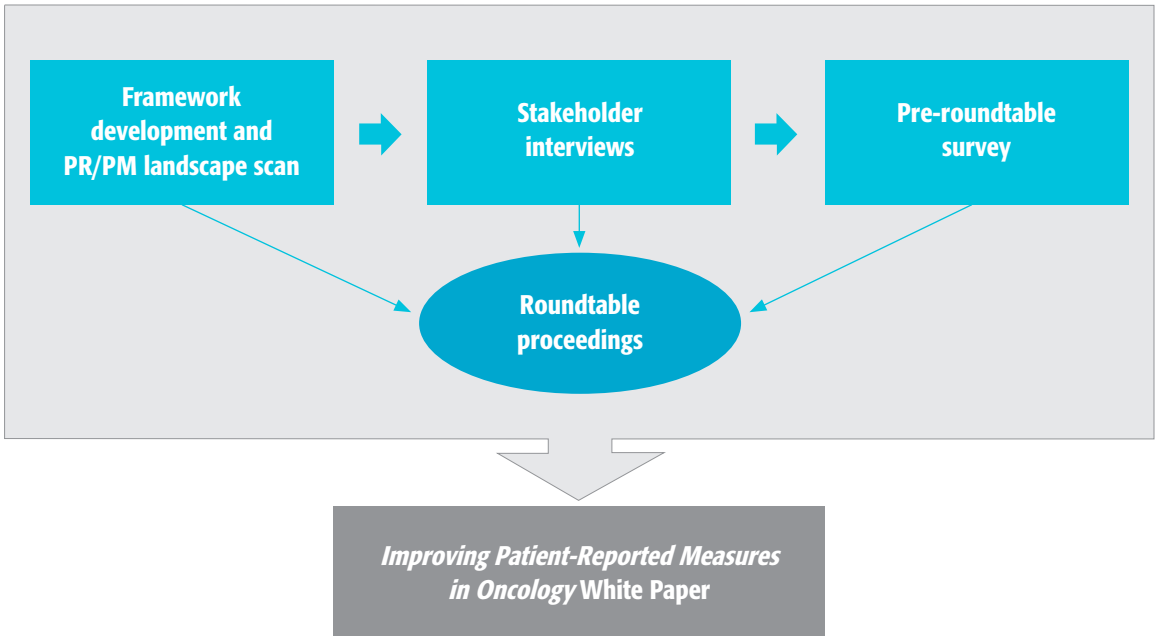
This report summarizes the findings from all four of these phases and offers recommendations derived from these findings. While the term "patient-reported outcomes" is common nomenclature, in this project, we did not restrict our discussion to purely "outcomes" measures and included, for example, measures of patient experience and measures that may capture patient reports on provider processes.

Because of this, throughout this paper we use the term "patient-reported measure" (PRM) to refer to the instruments that capture patient reports, and "patient-reported performance measure" (PR-PM) to refer to the quality measures used to assess performance, instead of "PROs" and "PRO-PMs," which refer specifically to outcomes.

METHODS

Discern began the project by reviewing literature, developing an organizing framework, and conducting a landscape scan of PRMs and PR-PMs in oncology and value-based programs. Next, we conducted interviews with roundtable participants and other stakeholders and experts in oncology care and measurement. The interviews informed the design of a pre-meeting survey administered to the roundtable participants. Finally, a multistakeholder roundtable convened patients and expert stakeholders to discuss the topic and develop recommendations for filling gaps in PRMs and PR-PMs and removing barriers to PR-PM implementation in accountable care programs related to oncology. Figure 1 illustrates the inputs to this report.

Figure 1: Report Inputs



Framework for Analysis

To organize our review of existing PRMs and PR-PMs, Discern explored the literature to identify various methods of classification that could be used to develop a framework for the landscape analysis. By determining critical measurement areas and the availability of PRMs and PR-PMs in these areas, we were able to more easily recognize gaps where no or insufficient PRMs and PR-PMs exist. First, we identified the key phases and nodes of oncology care and organized them into a high-level illustrative care model. Then we described domains of measurement to capture the facets of care that might hold value for oncology patients, providers, and payers.

Care Model

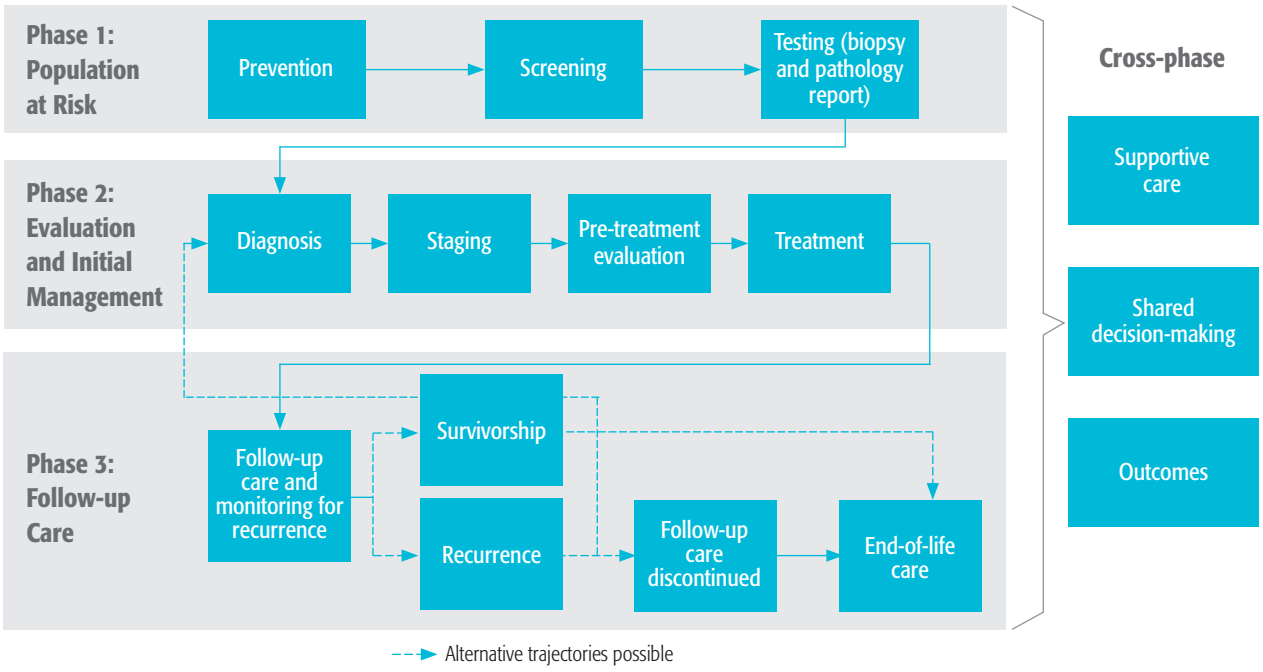
The 2017 Discern/NPC paper, *Improving Oncology Quality Measurement in Accountable Care*, catalogued the care models for specific cancers and identified measures and measure gaps related to clinical guidelines. The paper suggested that PROs should be collected before, during, and after treatment. The paper also emphasized the importance of cross-cutting measures, noting that "pursuing measure development for all possible opportunities would result in potentially burdensome data collection and reporting requirements for providers."[12] To evaluate whether existing PRMs and PR-PMs cover the most critical nodes of cancer care, we synthesized the condition-specific care models Discern described in our prior work, building in concepts from the NQF Patient-Focused Episodes of Care "Generic Episode of Care" model for cancer care, and validating the resulting model by consulting the National Voluntary Consensus Standards for Quality of Cancer Care.[13,14]

This illustrative care model identifies general nodes in the oncology patient pathway during the three phases: population at risk, evaluation and initial management, and follow-up care (see Figure 2).

- The **population at risk phase** covers the period of time prior to cancer diagnosis. This includes preventative activities, disease/risk screening, and testing.
- The **evaluation and initial management phase** includes the diagnosis, staging, pre-treatment evaluation, and treatment nodes of care.
- Finally, the **follow-up care phase** incudes discontinuation of care, follow-up and monitoring for recurrence, and moving into either survivorship or end of life.

PROs and experiences related to supportive care and shared decision-making may be captured at many nodes throughout this model and in relation to the care process as a whole and are labeled as "cross-phase" in Figure 2.

Figure 2: High-level Phases and Nodes of Cancer Care



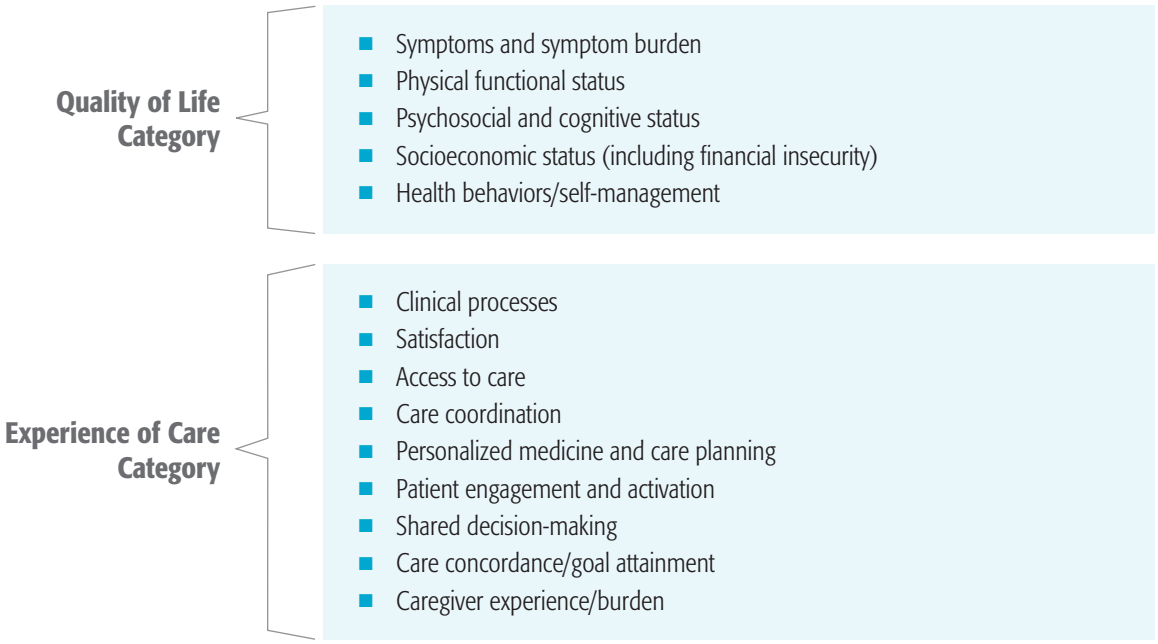
Measure Domains

Building on prior literature, Discern also identified 14 domains of measurement in two general categories to describe the range of PRMs and PR-PMs needed to capture quality and value in oncology care.

An American Society of Clinical Oncology Quality of Care Committee work group previously identified and recommended developing two different approaches for categorizing PRO-PMs in oncology.[15] The first approach involved outcomes measurement, including developing and using measures related to patient symptoms, overall functioning, and/or well-being. The second approach involved process measurement, which captures the care delivery process and patients' experiences with their providers. Following these approaches, Discern organized PR-PMs into the overarching categories of quality of life and experience of care. Within each of these categories, we identified a list of oncology domains by comparing and contrasting:

- priority areas of oncology PRO measurement from the Discern and NPC 2017 white paper, *Improving Oncology Quality Measurement in Accountable Care*;[16]
- Quality Oncology Practice Initiative (QOPI®) domain modules assessing key aspects of cancer care delivery;[17]
- PRO-PM domains from a 2017 Discern and Pharmaceutical Research and Manufacturers of America (PhRMA) paper, *Patient-Reported Outcome Performance Measures*;[18]

Figure 3: PRM and PR-PM Categories and Domains: Not Mutually Exclusive



- PRO domains from NQF's *Patient Reported Outcomes in Performance Measurement*;[19] and
- additional resources cited throughout.

Figure 3 illustrates the categories and domains we use throughout this report to classify individual PRMs and PR-PMs according to key measurement concepts in patient-centered care. The definitions we used to code PR-PMs into domains are displayed in Appendix I.

The **quality of life category** includes domains that capture individuals' perceptions of their physical, emotional, social, and financial status and their own level of engagement in health and treatment. The **experience of care category** includes domains that assess individuals' perceptions of activities that occurred (or failed to occur) throughout the phases of care, including their satisfaction with specific activities and overall care.

Rather than collapsing several key facets of experience together into larger domains, this more detailed taxonomy allowed Discern to highlight distinct ideas. These domains are not intended to be mutually exclusive classifications, and some PRMs and PR-PMs fall within multiple domains.

PRM and PR-PM Landscape Assessment and Gap Analysis

Discern Health conducted a landscape scan to assess the current environment of PRMs and PR-PMs in oncology, including their use in value-based delivery and payment models. The landscape review was aimed at creating an inventory of existing PRMs and PR-PMs related to oncology and applying the framework of care phases and domains to identify gaps.

In April 2018, we searched the NQF Quality Positioning System, Agency for Healthcare Research and Quality's (AHRQ) National Quality Measures Clearinghouse (NQMC),[ii] and Centers for Medicare and Medicaid Services' (CMS) Quality Measures Inventory for existing PR-PMs. We also identified oncology-related accountability programs to assess whether PR-PMs were included and ensured those measures were included in the inventory.

The list of PR-PMs was narrowed to those specifically referencing oncology or those that could be considered cross-cutting. We reviewed cross-cutting PR-PMs because prior NPC/Discern work found these measures are often included in accountable care measure sets to capture topics such as pain assessment, treatment planning, depression screening, health care utilization rates, and radiation.[20] CMS has defined cross-cutting measures as measures that are "broadly applicable across multiple providers and specialties."[21] In this project, "cross-cutting" refers to measures that were not oncology-specific but could include the oncology population and be applied to at least one of the phases of cancer care.

The list of oncology-specific and cross-cutting PR-PMs was coded into care phases based on what node(s), process(es), or interaction(s) in the illustrative care model each PR-PM assessed. Following the framework, we also classified existing PR-PMs into the 14 quality-of-life and experience-of-care domains described above.

We then identified the PRMs associated with each PR-PM for analysis. This list was supplemented by a literature review of a variety of sources summarized in Appendix II. We also coded the PRMs into our framework by evaluating the individual items (e.g., survey questions) in each instrument.

The PR-PMs and PRMs were then analyzed for apparent gaps: care phases and domains where few PR-PMs and PRMs were found. The results of this analysis will be discussed in depth later in this report. A full list of the identified oncology-specific PR-PMs and their associated PRMs can be found in Appendix III.

Subject Matter Expert Interviews

In preparation for the multistakeholder roundtable, Discern conducted interviews with 17 subject matter experts in patient experience, direct cancer patient care, quality measurement, health services research, and value-based payment (VBP) (see Appendix IV). The goal of the interviews was to gain insight from multiple stakeholder perspectives on the development and use of PRMs and PR-PMs in oncology and value-based care. The open-ended interviews were informed by a discussion guide (Appendix V), developed based on the information and insights gathered from the PRM and PR-PM landscape analysis and prior Discern/NPC research.[22] During the interviews, we did not rigidly adhere to the questions, but adapted the content to better allow participants to share their diverse perspectives.

[ii] NQMC was removed from the AHRQ website in July 2018. All measures included in this report were collected and assessed prior to that time.

Multistakeholder Survey

Prior to the roundtable, Discern administered a survey to the roundtable participants to build on interview insights and identify priorities for discussion during the roundtable. The survey covered:

- participant use of PRMs and/or PR-PMs in oncology or otherwise,
- experience with specific oncology PRMs,
- knowledge of PRMs and PR-PMs used in oncology programs,
- prioritization of measure domains for use in VBP for oncology,
- barriers to PR-PM adoption in VBP for oncology, and
- potential unintended consequences of VBP adoption.

A subset of the roundtable participants completed the survey (N=18), and the responses informed the content and direction of the roundtable.

Roundtable

The "Improving Patient-Reported Measures in Oncology" roundtable was a multistakeholder event focusing on the availability of and need for oncology-specific and cross-cutting PRMs and PR-PMs. The roundtable was held in Washington, D.C., on September 5, 2018, sponsored by NPC, and organized by Discern Health. Chaired by Drs. Mark McClellan, Director, Duke-Margolis Center for Health Policy, and Ethan Basch, Director, Cancer Outcomes Research Program, UNC Lineberger Comprehensive Cancer Center, the meeting aimed to develop actionable recommendations for filling PR-PM gaps and overcoming barriers to implementing meaningful PR-PMs in accountability programs.

The pre-roundtable research shaped the content and approach for the event, which was attended by 24 participants representing a variety of stakeholders in oncology care, regulation/policy, quality measurement, employer purchasing, academic research, health insurance, and patient advocacy. Two patients were among the participants, and many of these participants were also included in the stakeholder interviews. Eighteen of them also completed the pre-meeting survey. Appendix IV lists the interview and roundtable participants.

Discern, NPC, and the roundtable chairs prioritized elevating the patient voice during the proceedings by directly integrating patient perspectives into the conversation and resulting recommendations. The roundtable featured a patient panel as the first substantive item on the agenda (see Appendix VI). The patient panel was moderated by a patient advocate, who, as part of the panel proceedings, interviewed one current patient and one survivor about their experiences. The themes from this patient panel framed the context for the other roundtable sessions, and the patient representatives also participated in the larger discussions and breakout sessions throughout the day.

FINDINGS

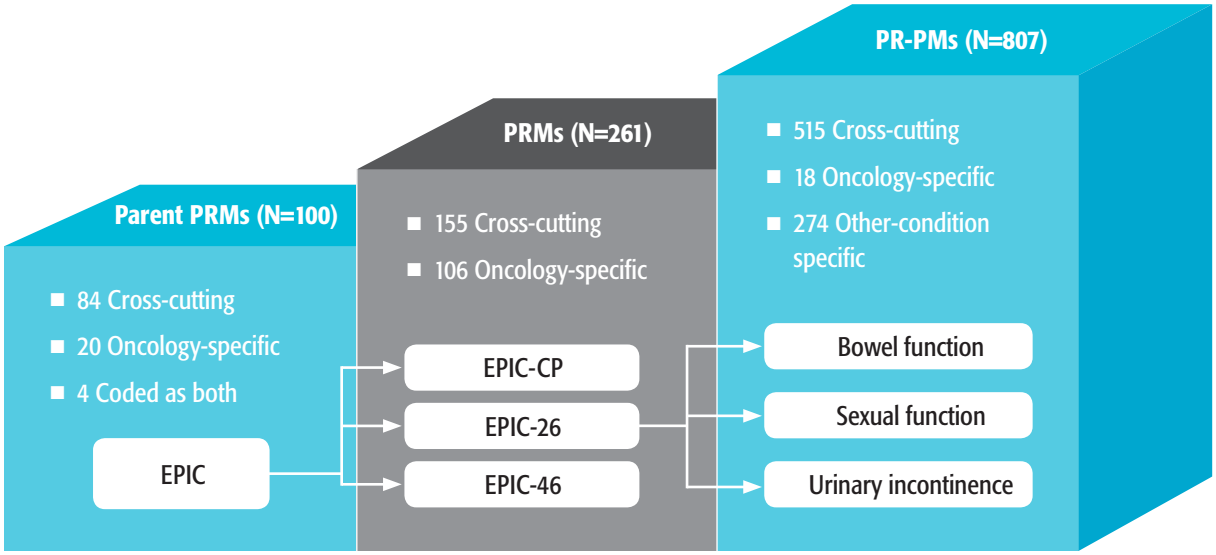
PRM and PR-PM Landscape Findings

Discern's landscape scan identified oncology-specific and cross-cutting PRMs and PR-PMs. Because many individual PRMs are derived from the same basic PRM or are part of a series, the term "parent PRM" was introduced. From the sources described in the Methods section above, we identified 20 parent PRMs, 106 PRMs, and 18 PR-PMs specific to oncology. We also found 84 parent PRMs, 155 PRMs, and 515 PR-PMs that were cross-cutting measures relevant to an oncology population. An additional 274 PR-PMs were specific to other conditions and thus excluded from the PRM search, domain categorization, and gap analysis.

Not all PRMs or parent PRMs were associated with PR-PMs, and some of the oncology-specific PR-PMs are based on cross-cutting PRMs. Additionally, many PR-PMs are calculated from items on the same PRMs. Figure 4 provides a summary of these key findings and an example of an oncology-specific parent PRM, with related PRMs and PR-PMs. The Expanded Prostate Cancer Index Composite (EPIC) is classified as a parent PRM of the EPIC-CP, EPIC-26, and EPIC-46 PRM instruments. Each of these instruments has associated PR-PMs. For example, the survey questions from the EPIC-26 support PR-PMs measuring the impact of treatment on patients' bowel function, sexual function, and urinary incontinence, respectively, when comparing a baseline PRM given at the beginning of treatment to the same PRM administered during follow-up.

See Appendix III for a list of oncology-specific PR-PMs and associated PRMs.

Figure 4: Summary of PRM and PR-PM Landscape Findings



Oncology-specific and Cross-cutting Measures by Care Phase and Domain

To better understand the use of measures across a patient's journey, we categorized the PRMs and PR-PMs into the care phases and measure domains introduced in the *Framework* section of this paper.

As mentioned above, the three main care phases used for evaluation were population at risk, evaluation and initial management, and follow-up care.

Key findings included:

- Many PR-PMs were coded as applicable to multiple phases, with some cross-cutting PR-PMs coded as relevant to all three phases of care.
- Oncology and cross-cutting PR-PMs were generally more applicable to the evaluation and initial management phases.
- No oncology-specific PR-PM was identified for the population-at risk-phase, which includes the period prior to cancer diagnosis (Figure 4).
- Similar results were observed for parent PRMs for oncology, with 100% (20 total) of parent PRMs applicable during the treatment phase, 20% (5 of 20) in follow-up care, and only 5% (1 of 20) in the population at risk phase (Figure 5).

In addition to identifying care phases addressed by PRMs and PR-PMs, Discern classified existing PRMs and PR-PMs into 14 different domains with the overarching categories of experience of care and quality of life. Figure 6 illustrates the number of

Figure 5: PR-PMs and PRMs in Cancer Care Phases

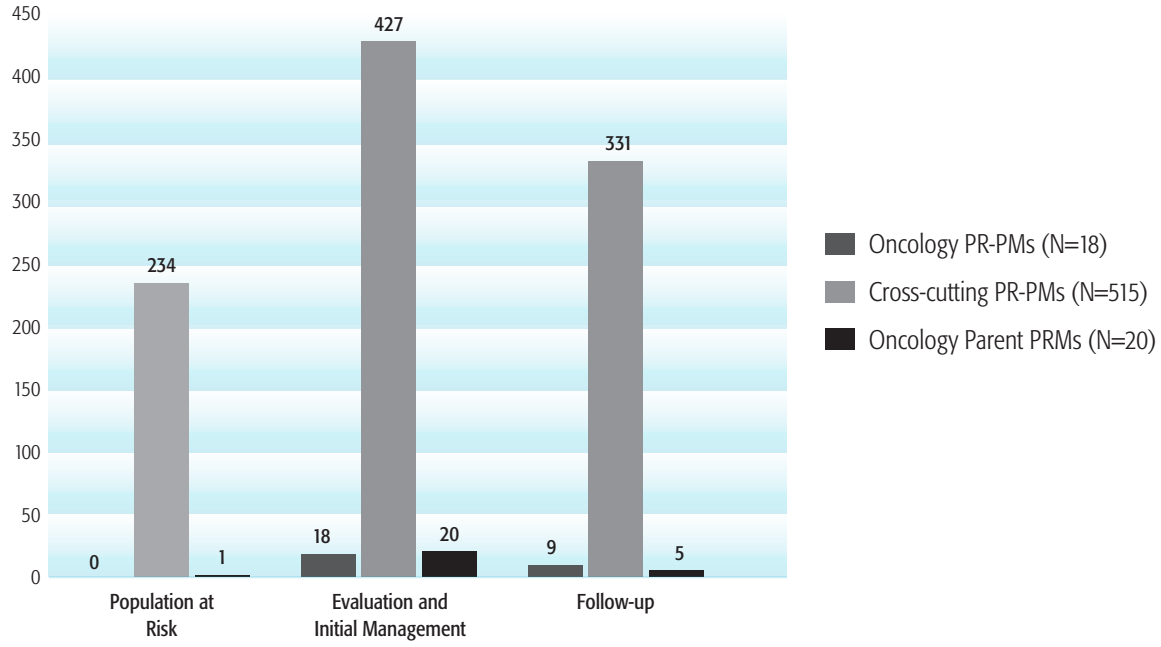
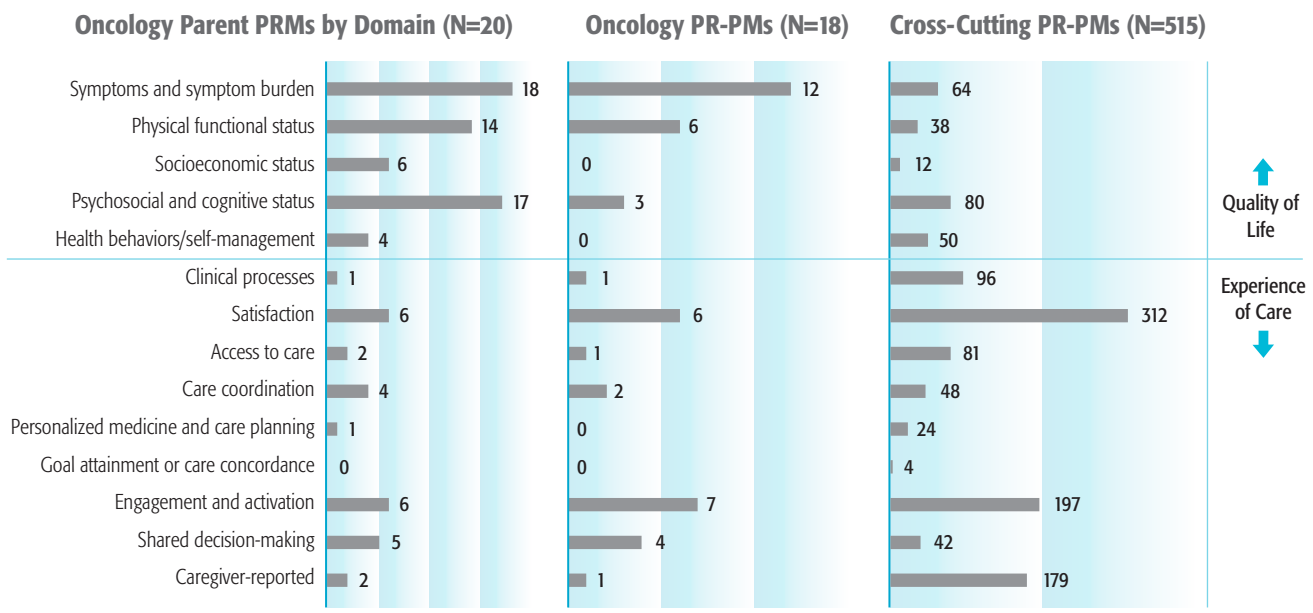


Figure 6: PRMs and PR-PMs by Measure Domains



parent PRMs, oncology-specific PR-PMs, and cross-cutting PR-PMs that were coded into each domain. The Discern analysis shows:

- Many PRMs and PR-PMs fall into multiple domains.
- About 90% of parent PRMs fall into quality-of-life domains, with 35% in experience-of-care domains.
- Compared to cross-cutting PRMs and PR-PMs, a higher percentage of oncology PRMs and PR-PMs focus on quality-of-life domains, including symptom and symptom burden, physical functional status, and psychosocial status.
- In the experience-of-care category, a significant number of PR-PMs are related to satisfaction for both oncology and cross-cutting areas; this domain dominates the cross-cutting PR-PMs.

Gaps in Current PRMs and PR-PMs

By categorizing the PRMs and PR-PMs into the described framework and evaluating the results, Discern identified areas that lack sufficient measures and may be considered during future development or modification of PRMs and PR-PMs. Discern's analysis shows that there are gaps in the availability of both PRMs and PR-PMs across the phases of care and domains of measurement.

Gaps Across Care Phases

- Only one of the oncology-specific parent PRMs, and no PR-PMs captures the **population at risk** phase of care. Understanding patients' health and experience during the early nodes in the care process can help providers assess preventive care and avoid future complications.

- Within the evaluation and initial management phase, a gap in PR-PMs relates to delays in diagnosis and communication of test results.
- Few oncology-specific PRMs and PR-PMs exist that are applicable to **follow-up care** (20% of parent PRMs and 1.7% of PR-PMs). These measures are needed to capture patients' experience and outcomes as they transition from active treatment into survivorship or end-of-life care.
  - Most existing PRMs and PR-PMs in this phase focus on end of life.
  - As cancer treatment advances, the survival rate is improving, and the National Cancer Institute projects 20.3 million cancer survivors by 2026.[23] This leads to larger numbers of cancer survivors and a greater need for PRMs and PR-PMs that capture the **survivorship** node of the follow-up-care phase.

Gaps Across Domains

- Few oncology-specific PRPMs exist related to:
  - **Goal attainment or care concordance** (0 oncology-specific and 4 cross-cutting)
  - **Socioeconomic status** (0 oncology-specific and 12 cross-cutting)
  - **Personalized medicine and care planning** (0 oncology-specific and 24 cross-cutting)
- The **clinical** process domain has 96 cross-cutting PR-PMs available, but we found only one oncology-specific PR-PM.
- There are also differences across the types of information captured in PRMs and PR-PMs. For example, 17 oncology-specific PRMs address **psychosocial and cognitive factors**; however, Discern only identified three PR-PMs that capture these factors. This is a gap considering the impact of diagnosis and treatment on the mental health and psychological state of patients and caregivers.
- Overall, about one-third of total PR-PMs fall under the engagement-and-activation domain, but most of these are related to provider communication and patient education.
  - Only a limited number of PR-PMs address patient behaviors that demonstrate **patient engagement** or **self-management**.
  - Likewise, few PR-PMs assess **level of engagement** or **efforts to promote engagement** across all stakeholders involved in a patient's care, including caregivers.
- Over one-third of total PR-PMs are caregiver-reported, but very few ask about **caregiver engagement**, **burden**, or **health**. Many of these measures are for the pediatric population and do not focus on caregiver experience.

By identifying gaps in current PRMs and PR-PMs, Discern was able to better understand the quality landscape for oncology and identify areas where measure developers and other stakeholders can develop new PRMs and PR-PMs or enhance existing ones. These opportunities were further explored in the interviews, survey, and roundtable proceedings, as discussed below.

Adoption in Payment Models

Along with identifying and classifying oncology-specific and cross-cutting PRMs and PR-PMs, another objective of the landscape scan was to explore how those measures are used for value-based delivery and payment. The findings present various CMS accountability programs that include PRMs. Some of these programs are specific to oncology, while others are cross-cutting programs with oncology application.

Oncology-specific Measures and/or Programs

Several CMS programs have implemented PR-PMs for an oncology-specific population and/or process measures that are not PR-PMs but capture use of a PRM. Programs include the Prospective Payment System (PPS)-Exempt Cancer Hospital Quality Reporting (PCHQR) program, the Merit-based Incentive Payment System (MIPS), and the Oncology Care Model (OCM). Appendix VII offers brief descriptions of these programs.

Table 1: PR-PMs in CMS VBP Programs

Program	PR-PM
PCHQR	■ **PCH-29**: Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) Survey - Cross-cutting; applicable to cancer treatment processes
OCM	■ **OCM-4**: Pain Assessment and Management Composite (not a PR-PM) - Component "Pain Intensity Quantified" indicates the presence of pain through use of a PRM ■ **OCM-5**: Preventive Care and Screening for Depression and Follow-Up (not a PR-PM) - Provider screening of patients using a PRM and subsequent care planning if screened positive ■ **OCM-6**: Patient-Reported Experience of Care ■ Excellent communication from health care professionals throughout cancer care (performance multiplier)
MIPS General Oncology Measure Set	■ **MIPS-143**: Oncology: Medical and Radiation—Pain intensity quantified (not a PR-PM) - Clinician-reported measure with a PRM component
MIPS Qualified Clinical Data Registries (QCDR)	■ **AQUA-29**: Prostate cancer—patient report of urinary function after treatment ■ **AQUA-30**: Prostate cancer—patient report of sexual function after treatment ■ **ONSQIR-20**: Fatigue improvement ■ **SMX-8**: Assessment and intervention for psychosocial distress in adults receiving cancer treatment (not a PR-PM; PRM component)
MSSP	■ **ACO-6:** CAHPS: Shared Decision Making ■ **ACO-18**: Preventive Care and Screening: Screening for Clinical Depression and Follow-Up Plan (Not a PR-PM; PRM component, see OCM-5 above)

Table 1 shows a list of PR-PMs used in these programs. It also includes several process measures that are not themselves PR-PMs but indicate the use of PRMs in the measures' specification. As previously noted, a full list of oncology PR-PMs, including stewards and endorsement status, appears in Appendix III.

Organizations are actively developing new PR-PMs for inclusion in MIPS. For example, the Pacific Business Group on Health received funding to develop two PR-PMs via a cooperative agreement award through the Medicare Access and CHIP Reauthorization Act of 2015 (MACRA) Funding Opportunity: Measure Development for the Quality Payment Program.[24] These measure concepts fit in the Oncology gap area:

1. Patient Reported Pain in Cancer Following Chemotherapy
2. Patient Reported Health Related Quality of Life in Cancer Following Chemotherapy

The American Academy of Hospice and Palliative Medicine also received a MACRA award to pursue two PR-PMs in the Palliative Care gap area that may be applicable to a cancer population. Based on the Hospice Consumer Assessment of Healthcare Providers and Systems (CAHPS®) Survey, these measures include:

1. Symptom measure—Percent of patients age 18 years and over receiving specialist palliative care who report getting the help they need for their [symptom]; on an item derived from the CAHPS Hospice Survey (whose respondents are bereaved caregivers) and modified for palliative care/seriously ill patient report
2. Communication Measure—Percent of patients age 18 years or over receiving specialist palliative care who report feeling heard and understood by their palliative care provider on the Heard & Understood item

Use of these oncology-specific PRMs in CMS programs indicates an interest in adopting PR-PMs; however, the limited number of such measures prompts the need for actionable recommendations for implementing meaningful PRMs and PR-PMs in VBP models.

Cross-cutting Programs with Oncology Application

In addition to oncology-specific measures and programs, there are accountability programs adopted by CMS for other providers and conditions that have applications for cancer care and include PR-PMs. Examples of such programs are presented in Table 2.

Table 2: Use of Cross-cutting PR-PMs in Other CMS Programs

Public Reporting
■ Medicare Compare Sites: Hospital, Nursing Home, Home Health, Hospice, Dialysis Facility ■ Qualified Health Plan Quality Rating System
Pay-for-reporting
■ Hospital Inpatient and Outpatient Quality Reporting Programs ■ Hospice Quality Reporting Program
VBP
■ MIPS and QCDRs ■ Medicare Star Ratings ■ Medicare Shared Savings Program and Next Generation Accountable Care Organization Model ■ Home Health Value-Based Purchasing
Other
■ Nursing Home Quality Initiative

Some of these programs, including the 2018 MIPS Qualified Clinical Data Registries (QCDRs) as described above, include PR-PMs specific to oncology. While most of these programs are not oncology-specific, many serve high-cost and high-need patients, including some with cancer, or address different components of cancer care. For example, the Hospice Quality Reporting Program imposes Medicare penalties if hospices fail to collect and report results from the Hospice CAHPS Survey. Hospice CAHPS is used to calculate eight PR-PMs that can include cancer patients during the follow-up care/end-of-life phase of the care model.[25]

In addition to the CMS programs listed, other entities have also created oncology-specific and cross-cutting programs that include PR-PMs or the use of PRMs. For example, to attain National Committee for Quality Assurance Oncology Medical Home Recognition, practices must meet an Oncology Quality Measures element by reporting six measures from a list of 37 cross-cutting and oncology-specific measures, 10 of which are PR-PMs or include the use of PRMs.[26] Contracts that may include PRMs or PR-PMs also exist between commercial payers and providers, and between payers and suppliers. For example, one interviewee from a health plan described a program requiring providers to collect and submit PRMs as part of their contractual agreements with the plan.

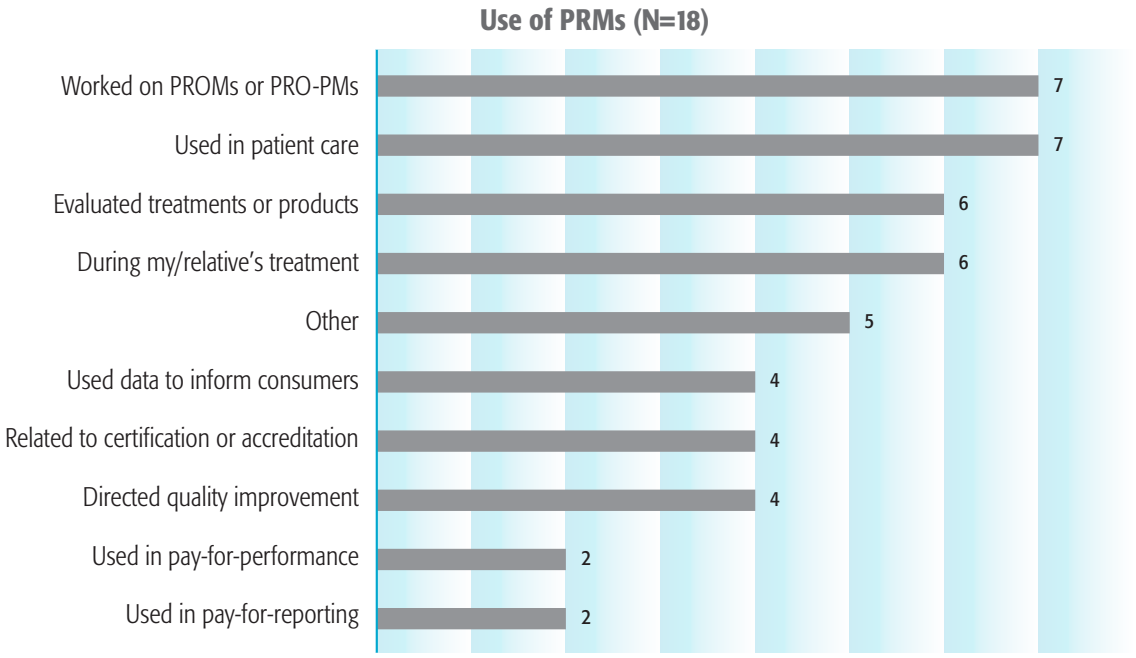
Survey, Interview, and Roundtable Findings

Participant Experience With PRMs and PR-PMs

One objective of the roundtable discussion was to understand the current use of PRMs and PR-PMs in oncology, including whether appropriate PRMs and PR-PMs are available and what gaps in measurement and implementation may exist. To assess the level of experience roundtable participants have with these measures, the pre-meeting survey asked, "How have you used PROMs and/or PRO-PMs in oncology or otherwise?"[3] Figure 7 shows the range of responses to this survey question. In addition to the multiple-choice responses represented in the chart, five participants also indicated other uses of these measures including uses relative to policy, PRO-PM endorsement, communicating patient perspectives to decision-makers, researching PROs for electronic health record (EHR) integration, and working to incorporate electronic patient-reported outcomes into the patient experience for a specialty pharmacy.

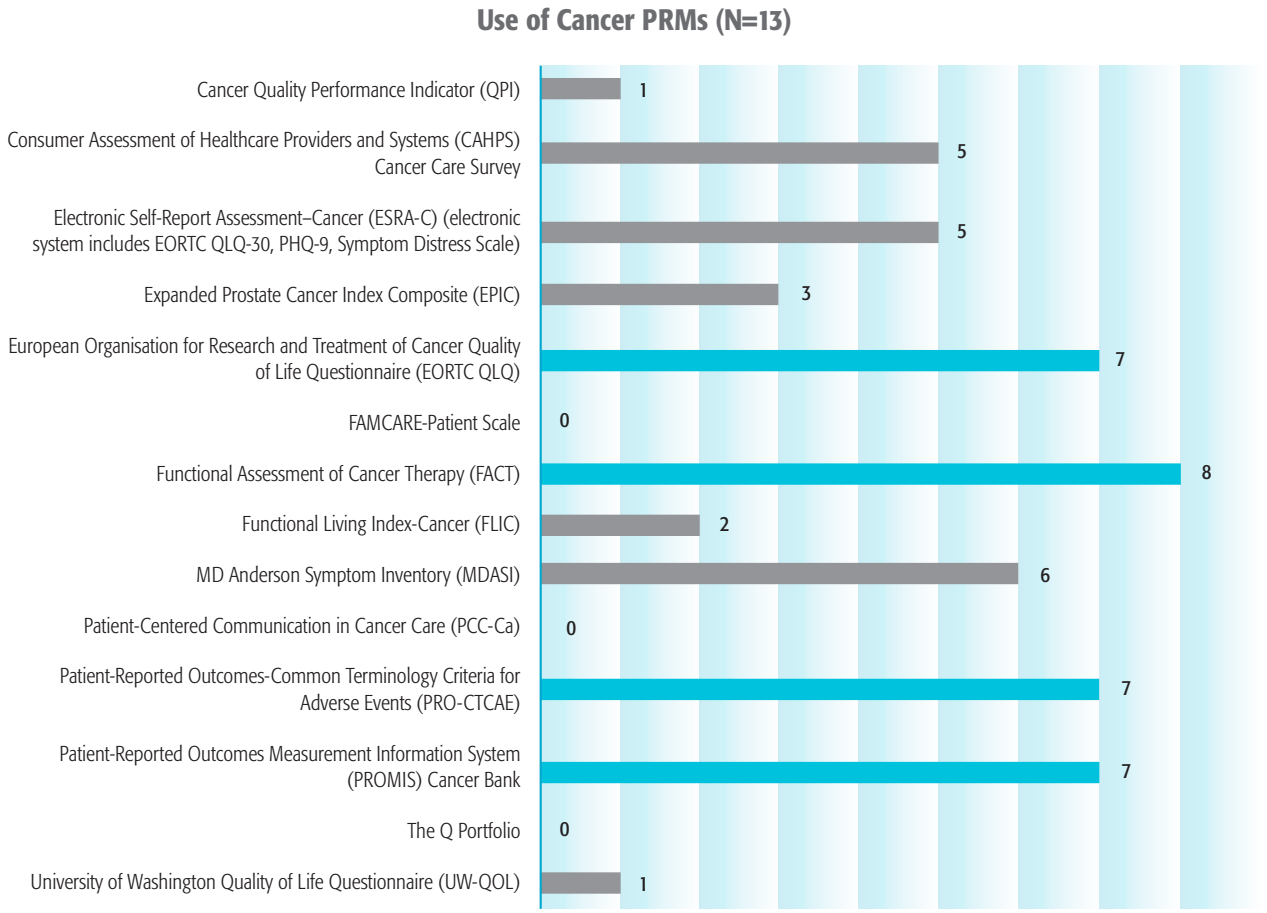
The survey also asked participants about specific PRMs they had used and which have been the most promising. Figure 8 indicates the number of respondents who used each PRM. The most frequently used are indicated in blue. In addition to those listed, respondents had used other tools, such as an internally developed PRM based on the Edmonton Symptom Assessment System; an Alliance of Dedicated Cancer Centers-developed measure; and cross-cutting PRMs such as the Short Form Health Survey, the Patient Health Questionnaire (PHQ-9), and the Patient-Reported Outcomes Measurement Information System (PROMIS) item banks.

Figure 7: Survey Respondent Use of PROMs and PRO-PMs[iii]



iii Project terminology was changed from PROM and PRO-PM to PRM and PR-PM after the survey had been administered.

Figure 8: Survey Respondent Use of Cancer PROMs



Survey respondents indicated that the instruments they have found most useful or promising for future development included:

- **PROMIS** because it is widely used, well validated, inexpensive (or free), and adaptive to multiple populations;[27]
- **Patient-Reported Outcomes version of the Common Terminology Criteria for Adverse Events (PRO-CTCAE™)** because it allows a seven-day recall period for patients to report symptoms;[28]
- **MD Anderson Symptom Inventory (MDASI)** because it assesses symptom severity;[29]
- **European Organisation for Research and Treatment of Cancer's (EORTC) quality of life questionnaires** because it is recommended by the International Consortium for Health Outcomes Measurement in its oncology Standard Sets;[30]

- **CAHPS Cancer Care** because it was developed specifically to compare across different clinics.[31] It is also used to inform decisions made by pproviders, patients and their families, accrediting organizations, and payers;[32] and
- **Functional Assessment of Cancer Therapy – General seven-item version (FACT-G7)** because it is brief (seven items) and therefore less burdensome to complete.[33]

These results are consistent with an August 2018 Medicare Evidence Development and Coverage Advisory Committee panel that supported incorporating PROMs into future clinical studies of Chimeric Antigen Receptor T-cell therapy for those with advanced cancer. The panel "voted with intermediate to high confidence that four tools used to measure patient-reported outcomes were valid and generalizable to the Medicare cancer population": EORTC's quality of life questionnaires, the PROMIS Cancer Bank, the PRO-CTCAE, and the MDASI.[34]

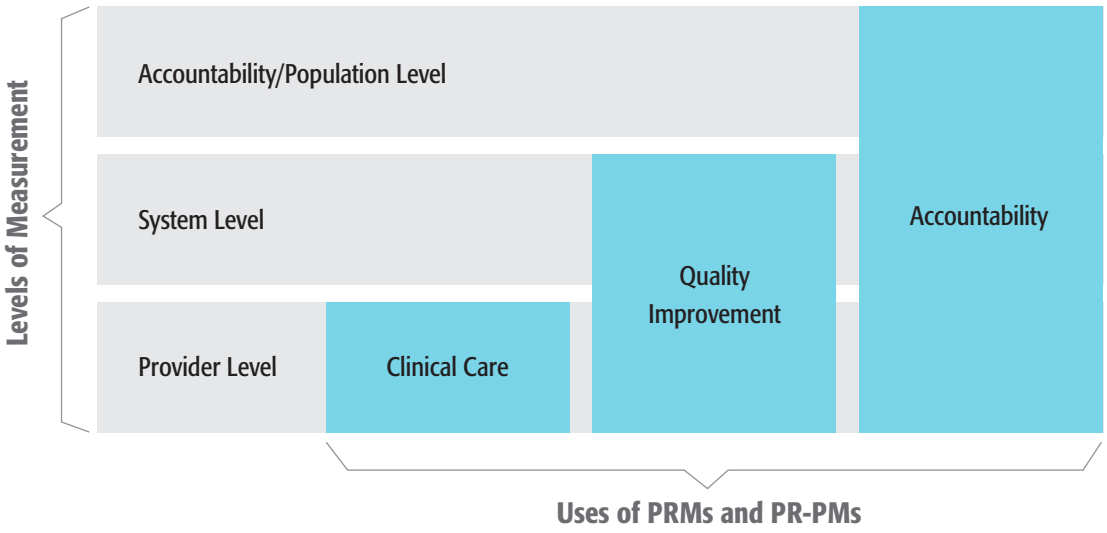
During the roundtable event, participants discussed their use of PRMs and PR-PMs in their personal and/or professional lives and elaborated on their diverse perspectives on the status of measures and opportunities for improvement. For example, one participant has developed several PR-PMs for use in value-based programs for areas such as cancer care and mental health (e.g., a depression reporting tool). One patient representative completes surveys on a regular basis and offered information on measures from a patient's point of view. These different perspectives sparked conversations on gaps in current measures and discussion on future interventions to eliminate those gaps, as described in detail below.

Use of PRMs and PR-PMs in Oncology

Prior Discern work with NPC identified a layered measurement approach that assesses performance at the provider, system, and external accountability levels.[35] Interviewees and roundtable participants built on this approach by considering three main uses of PRMs and PR-PMs that apply to the three levels. Figure 9 illustrates three uses of PRMs and PR-PMs in oncology care discussed by the roundtable to:

1. enhance **clinical care** at the provider level;
2. drive and measure **quality improvement** at the provider and system levels; and
3. assess performance for **accountability** purposes at the provider, system, and accountability/population levels.

Figure 9: Uses of PRMs and PR-PMs



Some PRMs and PR-PMs may be valuable at multiple levels and for multiple uses. For example, some PRMs of symptoms and symptom burden have clinical utility, can be used to assess and improve quality along with associated PR-PMs, and are the basis of PR-PMs that serve as rich resources for inclusion in accountability programs. Although NQF requires that "the intended use of the measure includes both accountability applications … and performance improvement to achieve high-quality, efficient healthcare"[36] as a condition for endorsement, not all existing measures are appropriate for all three uses.

A fourth use, research, was mentioned in interviews and during the roundtable but not discussed in great detail. PRMs and PR-PMs are used in academic research and in clinical trials to evaluate the effectiveness of treatments and increase adherence.

Clinical Care

Roundtable participants noted that PRMs may be effectively used in clinical care to help providers track changes in patient condition over time, identify the need for interventions, assess the impact of treatment, and facilitate conversations with patients and families. PRMs may also be used to educate patients about what symptoms to expect or which services are available. For example, one patient representative shared that many cancer patients are not informed about survivorship plans, which play a significant role in continued improvement of a patient's health and reduction of future complications after treatment ends. A PRM that includes a question to assess patient interest in or need for survivorship support could help ensure that patients receive needed services.

PRMs can be used to enhance the care delivered by oncologists as well as other providers. For example, one patient described their relationship with a specialty pharmacy clinic as one of the most valuable components of their care, built over 53 months of interactions. The patient noted that they had more frequent conversations with the pharmacy staff than other members of their oncology team.

In the pre-meeting survey, participants were asked whether each of the 14 measure domains was high, medium, or low priority for use in clinical care. The domains with the largest percent of respondents indicating "high" were symptoms and symptom burden (100%), physical functional status (94%), shared decision-making (94%), and health behaviors/self-management (88%).

Quality Improvement

PRMs and PR-PMs may be used for quality improvement to evaluate current performance, benchmark with other organizations, compare providers within an organization, and track organizational performance over time. Standardization of tools within and across organizations and over time is necessary for organizations to establish benchmarks, inform improvement activities, and measure progress. Participants noted that implementing PRMs and calculating PR-PMs is not sufficient for creating successful quality improvement programs; continuous monitoring and follow-up are required to improve outcomes.

Survey respondents had varied responses regarding the importance of PRMs and PR-PMs in each domain for quality improvement. Seventy-five percent (75%) rated symptoms and symptom burden as "high" priority, followed by care coordination (67%). Access to care, physical functional status, and personalized medicine and care planning were all deemed high priority by 56% of respondents. Socioeconomic status/social determinants of health and health behaviors/self-management had the most "low" priority responses at 25%.

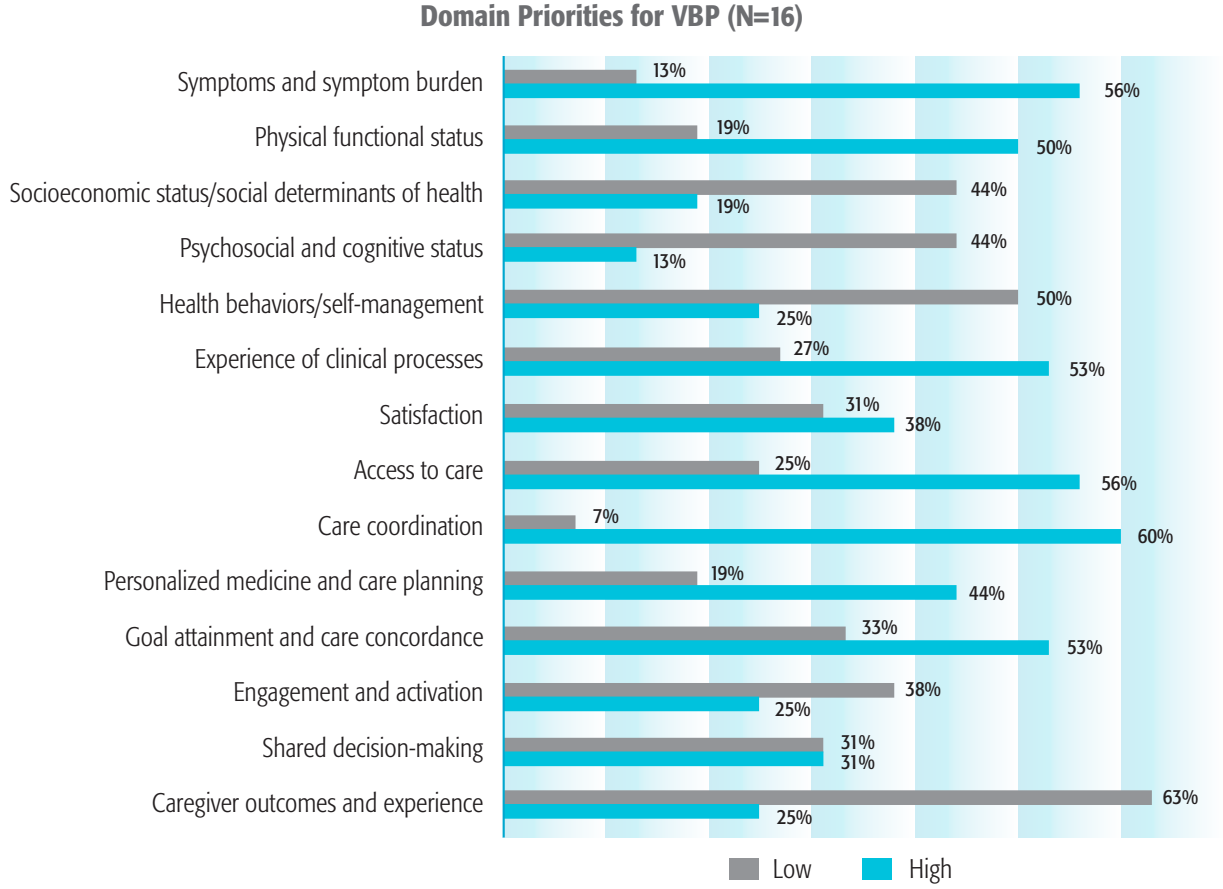
Accountability

PR-PMs can be used to hold health care entities accountable for performance through quality programs, VBP programs, and public reporting. Roundtable participants suggested that PR-PMs used in accountability programs should be held to a higher technical standard than PR-PMs for quality improvement to ensure that the regulatory or financial consequences of performance align with real quality of care. To develop or select "airtight" PR-PMs for accountability, program designers should consider cross-cutting PR-PMs that can be applied to and tested for use in larger populations and develop well-defined scales for evaluating performance. Participants also recommended developing a set of common PR-PMs for broad use and sharing and testing data across care settings.

The pre-meeting survey also asked participants to assess the priority (high, medium, or low) of each of the 14 measure domains for use in VBP programs. Figure 10 shows the percentage of participants who rated each domain as high (blue bars) or low (gray bars). Use for VBP had more varied results than clinical care or quality improvement, with 60% of respondents listing care coordination as "high," followed by access to care and symptoms and symptom burden (56% each). Caregiver outcomes and experience had the greatest proportion of "low" responses, at 25%.

Regardless of the context and purpose of the measures, interviewees and roundtable participants asserted that PRM development and implementation should always start with the patient and account for how providers, payers, policymakers, and consumers will respond to the results.

Figure 10: Survey Results on Measure Domain Priorities for VBP

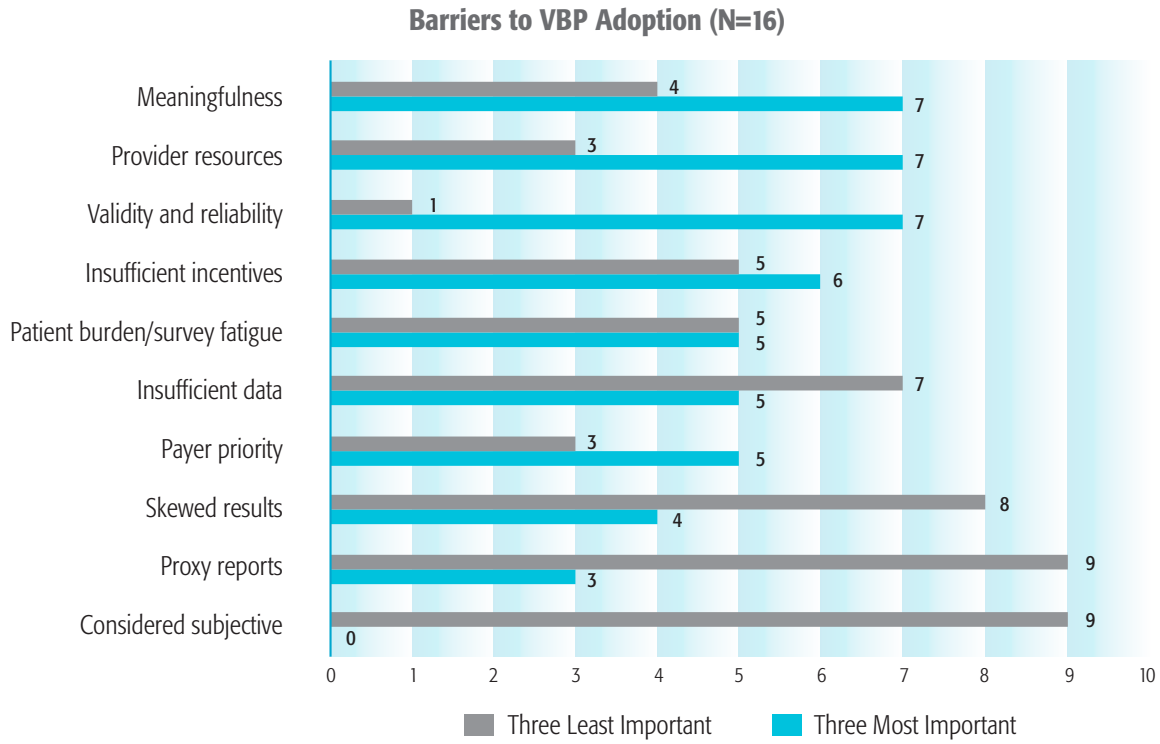


Barriers to PR-PM Implementation in VBP, and Potential Solutions

Although the Discern landscape scan identified over 100 PRMs and 18 PR-PMs specific to oncology, interview and roundtable participants described several barriers to the adoption of PR-PMs in VBP programs.

Interview participants highlighted core implementation challenges that ranged from those that could be described as methodological to those specific to providers and patients. These responses were used to develop a question on the pre-roundtable survey, which asked participants to indicate the three most and three least important barriers to address for facilitating VBP implementation. Figure 11 shows the number of survey respondents who indicated whether each barrier was in the top three (blue bars) or bottom three (gray bars).

Figure 11: Survey Results on Prioritizing Barriers to PR-PM Adoption for VBP



Based on the survey results and pre-roundtable interviews, Discern, NPC, and the roundtable co-chairs selected five barriers for small-group discussion during the roundtable: lack of meaningfulness of PRMs and PR-PMs, limited provider resources and insufficient incentives (combined into a single discussion because the topics were so intertwined), validity and reliability of PRMs and PR-PMs (expanded to encompass a constellation of methodological barriers), and patient burden/survey fatigue. Though payer priority and insufficient data were flagged in the "top three" by as many respondents as was patient burden, the latter barrier was emphasized in several interviews and selected for the roundtable to reflect the central importance of patient voice in the proceedings.

The selected barriers correspond to NQF's criteria for evaluating measures for endorsement, as shown in Figure 12.

Figure 12: NQF Evaluation Criteria Mapped to Selected PR-PM Implementation Barriers[37]

Importance to Measure and Report: "Extent to which specific measure focus is evidence-based and important to making significant gains in healthcare quality where there is variation in or overall less-than-optimal performance."[38] This corresponds with the **lack of meaningfulness** barrier.

Scientific Acceptability of Measure Properties: "Extent to which the measure, as specified, produces consistent (reliable) and credible (valid) results about the quality of care when implemented."[39] This corresponds with **methodological** barriers.

Feasibility: "Extent to which the specifications, including measure logic, require data that are readily available or could be captured without undue burden and can be implemented for performance measurement."[40] These concepts are related to **provider resources/insufficient incentives** barriers and the **patient burden/survey fatigue** barrier.

Usability and Use: "Extent to which potential audiences … are using or could use performance results for both accountability and performance improvement to achieve the goal of high-quality, efficient healthcare for individuals or populations."[41] This aligns with the **lack of meaningfulness** barrier.

Related and Competing Measures: "If a measure meets the above criteria and there are endorsed or new related measures … or competing measures … the measures are compared to address harmonization and/or selection of the best measure."[42] The need to align around standardized PRMs is discussed in the **limited provider resources/insufficient incentives** and the **patient burden/survey fatigue** sections.

Roundtable participants were separated into groups and asked to complete a root cause analysis on an assigned barrier. The goal of this exercise was to gain more insight on the biggest contributors to the barrier and devise possible solutions or interventions to mitigate some of the challenges. The following subsections summarize the output of this exercise, combined with other observations from throughout the day and insights from the pre-meeting interviews.

Methodological Barriers

The methodology used to develop PR-PMs in accountability programs is critical: If providers are incentivized to focus on and improve their performance on specific measures, these measures must be both scientifically sound measures of patient outcomes or experience and effective differentiators among providers. The interviewees suggested that PR-PM developers ensure that they are answering

two key questions about the methodology around capturing PRMs: 1) "Are we trying to measure the right things?" and 2) "Are we actually measuring what we think we are measuring?"

Challenges with answering the first question are explored in the *Meaningfulness* section below. Once developers have selected meaningful concepts and developed PRMs and PR-PMs that are also broadly meaningful, other methodological challenges may prevent developers from answering the second question and adequately assessing the concept being measured. These challenges include: creating measures fit for purpose, ensuring measures are scientifically sound, addressing potential biases, constructing functional denominators, and adjusting for risk.

Fit for purpose: To support the development of a PR-PM, an underlying PRM must fit the purpose for which it is expected to be used, take a form appropriate for target respondents (e.g., electronic versus paper surveys), and capture a variety of different outcomes and experiences. One decision point relates to the intervals during the course of treatment at which the PRM is administered.

To ensure that the PRM is "fit for purpose," participants emphasized the importance of first reaching an agreement on what the purpose is and selecting or creating a PRM relevant to the PR-PM that will be calculated from it. Though they are not always versed in survey design and measure science, many providers modify PRMs for their own use that were not initially designed for that purpose. While perhaps clinically useful, "tweaked" PRMs are not valid for benchmarking and accountability.

Scientific soundness (reliability and validity): The scientific acceptability of measure properties is an essential criterion for NQF evaluation and is defined as "the extent to which the measure, as specified, produces consistent (reliable) and credible (valid) results about the quality of care when implemented."[43] PRMs must undergo rigorous scientific testing to ensure that they have been developed to be both reliable and valid before being implemented.

Potential biases: PRM data may be impacted by potential biases in several ways. Developers must consider the sociodemographic and clinical characteristics of the patients who will be completing the PRM to ensure that the format and administration meet their needs (see *Patient Burden* section below for further discussion). Participants with certain characteristics may be less likely to respond to PRMs, and the time and place where a PRM is administered may impact both the likelihood and content of patients' responses. Lack of access to care across sociodemographic categories also creates difficulty validating measures across populations and leads to underrepresentation of some populations.

Another potential bias may arise from a lack of respondent anonymity. Patients may feel pressured to report favorable outcomes and "protect" their physicians or their relationships with those physicians.

Providers may also deliberately introduce bias in an effort to "game the system" by "cherry-picking" less complex cases and choosing less meaningful "check-box" measures that are easier to control. For example, providers may find it easy to perform well on a PR-PM that assesses the percentage of patients who reported whether they got any reminders about tests, treatment, or appointments from their provider's office between visits.

Some accountability programs, such as the Hospice Quality Reporting Program and the Home Health Quality Reporting Program, require providers to outsource administration of PRMs to external vendors, who collect surveys and ensure anonymity.[44,45,46] While this may minimize bias for accountability purposes, it removes the possibility of using survey responses to inform clinical care and reduces their utility for quality improvement.

Functional denominators: PR-PMs designed for a specific population may have small denominators, limiting the adequate testing of measures in development and increasing the risk that "outlier" responses will unduly impact performance. Participants noted the importance of having a large number of respondents to minimize biases, and suggested that implementing cross-cutting measures that are not specific to a type of cancer or treatment may support larger denominators and facilitate comparison across programs. Discern and NPC described additional techniques for addressing small numbers in our 2017 white paper.[47] These included building on AHRQ principles by using composite measures, reporting at the group level, and combining data across years or payers.[48]

Risk adjustment: Appropriately adjusting for risk is another critical factor in the transition from PRMs to PR-PMs to combat biases and create a fair playing field for provider performance. Risk adjustment often occurs based on patient acuity, demographic characteristics, socioeconomic status, and region. This process may be particularly challenging in oncology given the diversity of disease types, stage, tumor markers, and other clinical characteristics.

Discern and NPC's 2017 white paper recommended funding for measurement science around PROs related to payment models. CMS and others have now set aside funds for such efforts as evidenced by 1) the MACRA funding opportunity described above and 2) the active PR-PM work underway at CMS and the National Cancer Institute of the National Institutes of Health described by roundtable participants and interviewees.

In spite of federal support for developing new PR-PMs for accountability programs, **multiple project participants reflected on the methodological barriers highlighted above and expressed reservations about using the PR-PMs that exist today in VBP programs at all**.

Limited Provider Resources and Insufficient Incentives

Providers take the brunt of the responsibility for implementing PRMs and PR-PMs: building the infrastructure to administer PRMs, capturing quality data, reporting PR-PMs, and using data to improve patient care. A primary barrier identified through the roundtable discussion is lack of sufficient provider resources to collect, report, and analyze PRM data. This is problematic for VBP because providers with fewer resources might perform worse on PR-PMs than more affluent providers. This barrier also creates challenges in meeting the "Feasibility" NQF endorsement criterion.

Roundtable participants and interviewees discussed limitations to provider resources related to information technology (IT), availability of staff, time and provider priorities, PRM administration logistics, access to appropriate data, and insufficient incentives to offset needed resources. Participants also noted potential interventions for addressing these limiting factors.

IT: A solid IT infrastructure is critical for enabling providers to adopt PR-PMs. Participants noted that high technology costs add to the burden of implementing and using EHRs. They also identified

interventions to overcome IT-related challenges, such as:

- incentivizing technology vendors to integrate PRMs into their current platforms,
- developing (or enhancing) a technology platform to address interoperability and provide built-in opportunities for follow-up with patients, and
- incorporating IT features to facilitate patient understanding and completion of PRMs.

Staff availability: The collection and analysis of PRM data are time-consuming activities that create a strain on current staff or require providers to hire additional supporting staff. Insufficient staff training, lack of staff availability, staff member age, access to specialty staff who accept the importance of capturing the patient voice, and lack of proper infrastructure were all listed as factors related to shortages of staffing resources for providers.

To address these factors, the roundtable participants encouraged providers and other stakeholders to:

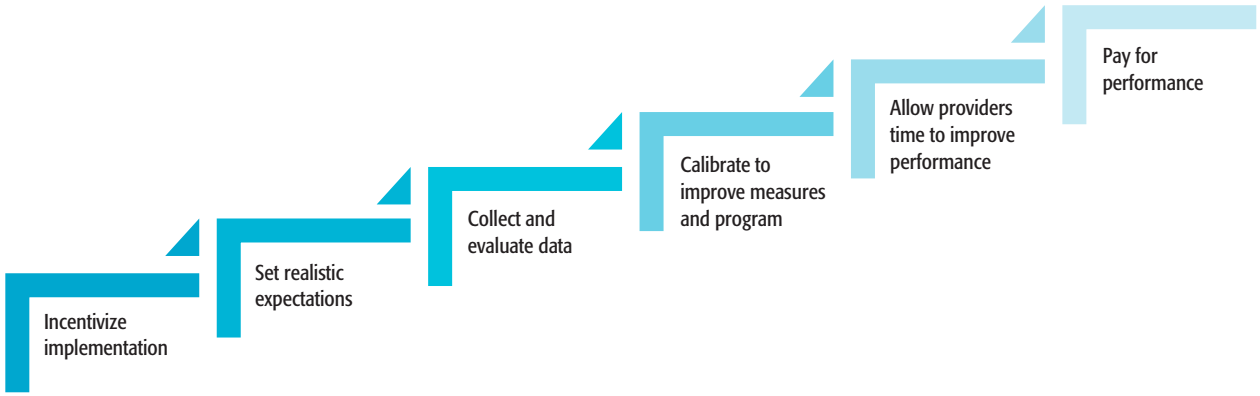
- implement training programs that focus on the importance of PRMs and PR-PMs;
- delegate PRM administration and tracking to lower-cost resources (e.g., supporting staff, instead of physicians or nurses);
- provide interdisciplinary staff (e.g., dieticians, social workers, psychologists) access to PRMs and educate them on how to use the information;
- utilize community resources if available, and engage care coordinators or patient navigators to work with patients and assist providers through PR-PM adoption;
- work with EHRs to streamline the work flow for data collection; and
- align PRMs and PR-PMs across programs, and source PRMs from existing or standardized instruments to decrease assessment burden.

Time and priority: Despite the move toward value-based care, physicians have limited time with individual patients, in part because they are still compensated for the volume of patients seen and services provided as opposed to the value of care being provided. Physicians must prioritize tasks and delegate to supporting staff to ensure an appropriate amount of time is spent with patients. Because different payers and programs also have different quality and reporting requirements, providers also struggle to understand and prioritize the activities to meet program demands.

To improve the infrastructure and mitigate provider limitations, roundtable participants suggested that health plans become more involved by offering more centralized support and coordinating access to the resources needed to administer and process PRMs. Providers can also save time with access to additional resources, such as timely data and improved IT features (e.g., automated visit notes generated through natural language processing). Finally, a standardized PRM offered by a federal organization would mitigate resource deficiencies. This instrument might be built from one that has already been created or be a new PRM designed to meet multiple needs.

Insufficient incentives: Discern and NPC's 2017 white paper suggested the need to incentivize collecting and using patient-reported tools, and this recommendation was emphasized and expanded during the 2018 roundtable. Provider burden increases and the motivation to adopt PRMs decreases when accountability programs do not incorporate incentives that are sufficient to offset the costs of implementation, administration

Figure 13: Stepwise Approach for PR-PM Implementation in VBP Programs



of PRMs, and reporting of PR-PMs. This challenge may be addressed by offering higher financial incentives for reporting or performance, including for performance improvement in direct and downstream outcomes over time.

To implement PR-PMs in VBP, one participant suggested a "crawl, walk, run" approach, also described as "collect, review, respond." CMS and other payers should support the needed resources to facilitate each stage of PRM and PR-PM implementation for VBP. Using a stepwise approach (Figure 13) that culminates in paying for performance, payers should:

1. incentivize implementation and improve resources for payers and providers to simplify the collection process;
2. set realistic expectations for implementation and performance (including validated thresholds);
3. build in time for providers and programs to gather and analyze data (possibly during a pay-for-reporting period);
4. calibrate approaches to improve program structure, PRMs, and PR-PMs based on lessons learned;
5. give providers time and information to improve performance toward the PR-PMs; and
6. institute "pay for performance" and begin evaluating additional PR-PMs.

Patient Burden and Survey Fatigue

Research shows that concerns over patient burden, resource constraints, and the need for easily administered assessment tools often act as barriers to quality measurement.[49] Participants did not believe that patient unwillingness to complete PRMs is a significant barrier for PR-PM implementation in accountability programs; in their experience, oncology patients are usually willing to provide feedback and complete surveys as needed to improve care delivery. However, completing PRMs can place a significant burden on patients, undermining the NQF evaluation criterion of "Feasibility".

Patient burden is compounded by large numbers of surveys for patients who see multiple providers; irrelevant, complex, and/or redundant questions that often lead to survey fatigue; inconvenient methods of administration; and a lack of understanding about if and how the information provided will be used.

Multiple PRMs with redundant questions: Due to lack of coordination between providers and programs, patients receive many surveys that can be extensive and duplicative. According to one patient representative, patients receive one to four surveys per appointment and may have multiple appointments in a given week. Through data sharing and EHR integration, health care providers can reduce the number of PRMs a patient is asked to complete and eliminate duplicate questions, thus reducing patient burden. Implementing brief questionnaires, such as FACT-G7, also allows for a less burdensome and more facile administration process.[50] Another challenge/opportunity is selecting or developing a standardized PRM that fits a variety of purposes without adding to patients' burdens. To help justify the burden, providers and payers might consider offering patients incentives to complete PRMs.

PRM questions lacking relevancy: Because PRMs may be developed to serve a range of purposes for a variety of patients and providers, not all questions are relevant to all patients. To improve relevancy, the principles of computer adaptive testing might be applied to PRM administration: The questions asked later in an instrument would depend on the patient's characteristics, answers earlier in the instrument, or answers on previous instruments. Sometimes questions may not seem relevant to the patient but may be important for care or research. Including explanatory text may help mitigate this issue. Finally, one interviewee observed that some questions are "triggering" or cause distress. Participants noted that PRMs should always include options that allow patients to opt out of specific questions or future surveys.

PRM administration: The method of PRM administration (e.g., phone, mobile device, computer, or mail-in) may also increase burden for patients who have lower health literacy or are not fluent in the language or languages in which the PRM is administered. These challenges may be addressed by offering different methods of completion, providing resources to help patients understand and complete PRMs, and making the instruments adaptable to a variety of populations.

Patients not knowing how PRM data is used. According to patients and patient advocates, patients want to know how the information they are submitting on PRMs will be used, but do not have visibility into the process and often suspect that the information is collected but not used. Patients do not often have access to the tools and information they would need to understand how PRMs translate to PR-PMs for provider accountability or quality improvement, and do not see their providers using PRM responses during clinical practice.

To provide quality care and keep the focus of PRM and PR-PM adoption on patients, it is critical that patients know why they are being asked the questions included in PRMs and what will happen with the data requested. A feedback loop, with providers giving feedback to patients after collecting data, is needed to build patients' confidence in the process. Since patients and caregivers are the ultimate care coordinators, they may also be engaged in the process of translating PRM responses into actionable information for improving care and outcomes.

Lack of Meaningfulness

A key concern noted in interviews, presented during the patient panel, and discussed throughout the roundtable proceedings was the meaningfulness of measures. The adoption of PR-PMs in accountability programs has increased providers' incentives to perform well on individual measures, including PR-PMs, and this makes the need for PRMs and PR-PMs to be patient-centered even more critical. The promise of value-based care is that payment

will be tied to value. However, the way VBP program designers define value may not always be meaningful to patients, caregivers, and providers.

CMS has recently emphasized the importance of meaningfulness through the launch of its "Meaningful Measures" framework, which is intended to focus quality measurement on what is important to patients, families, and caregivers, and align care with their goals and preferences. This initiative is also intended to improve the alignment of measures implemented in programs.[51]

One of the NQF criteria for measure evaluation, "Importance to Measure and Report," describes meaningfulness as follows: "for measures derived from patient reports, evidence should demonstrate that the target population values the measured outcome, process, or structure and finds it meaningful."[52] For NQF, this requires involving patients in the identification of structures, processes, and outcomes for performance measurement.

There is a consensus on the prioritization of meaningfulness when developing PR-PMs, but the development and implementation of meaningful PR-PMs is stymied by challenges associated with subjective definitions of "meaningful," difficulty engaging patients and caregivers in development activities, and lack of meaningfulness for providers.

Subjective definitions of "meaningful": Constructing a standard definition of "meaningful" is a challenging exercise for health care stakeholders. The exercise, however, is necessary to ensure that providers are held accountable for PR-PMs that capture true value for patients, providers, and payers alike. Among patients, the definition of "meaningful" can vary by individual, disease stage, and outlook. Different patients may have different treatment goals and definitions for symptoms and outcomes. For example, Discern and NPC's 2017 study noted that the implementation of measures related to symptoms and symptom burden must be adjusted for patient preference, as some patients may elect to pursue treatments that increase symptoms because of the expected benefits.[53]

During the patient panel, patient representatives identified survey questions they have encountered that best capture information they perceive to be meaningful:

- Over years of treatment, the best and most meaningful question one patient encountered is, "What have you done for yourself that you would want to share with another patient?" While this question does not ask about the care the patient received from their clinical team or health/treatment outcomes, it captures feedback that can be used to enhance the treatment experience for other patients with similar health problems. Knowing that their response could improve care for others increased the importance of this question for the patient.
- For another patient representative, the most meaningful questions have been, "What has your experience been?" and "Where do you see yourself five years from now?" The patient had survived a challenging treatment process, and these questions allowed them to reflect on their experience and look forward to a better future.

Even when the initial concept is meaningful to patients, the measure itself may be less so. For example, many PRMs capture a symptom at a point in time and miss true symptom burden. Likewise, PR-PMs in the category of experience of care often capture steps in care, but not if those steps were effective. Standardized program measures may measure the "right things" for many cancer patients while failing to be unique and precise enough for specific populations. This is a concern

for accountability programs because payers may attempt to evaluate the quality of care based on the performance of PR-PMs instead of assessing whether providers are using PRMs to learn what matters to patients and personalizing care.

Though the definition of "meaningful" varies across individuals, the patient panel noted the impact that meaningful questions and measures may have on patient engagement in the quality measurement process. **Not all PRM questions that are meaningful to patients may translate into PR-PMs appropriate for accountability, but the techniques described in the remainder of this section can help ensure that many of those PR-PMs are meaningful to patients**.

Difficulty engaging patients in development: To ensure PRMs and PR-PMs are meaningful, measure developers should capture the voices of patients and caregivers along the full spectrum of the development process, from identifying development priorities to designing, testing, and implementing PRMs and PR-PMs. Because patient needs change throughout treatment, PRMs should be evaluated for meaningfulness across the care phases, especially at key pivot points where care changes.

Specific challenges related to engaging patients include time commitment, operational costs to developers, and the complexity of PRM and PR-PM development. While participants agreed that patients are generally willing to engage in the development process, they also emphasized the need for patient incentives to enhance engagement. Financial incentives may increase expense related to PR-PM development, but developers should consider other areas for cost reduction that do not compromise patient engagement.

In addition to new PRM and PR-PM development, stewards and payers should also engage patients in the evaluation of already-developed PRMs and PR-PMs. Roundtable participants suggested that stewards and program administrators create "feedback loops" to foster continuous measure improvement with the following goals:

- Make the PRM collection process itself more meaningful to patients by verifying that the purposes of the PRM and individual questions are clear and patients know how the data will be used.
- Identify and eliminate ambiguity in questions and response scales, and ensure that patients have the information needed to respond.
- Make individual response data and PR-PM performance data available to patients.

Meaningfulness to providers and actionability: While patients should be at the center of the process for quality measurement, meaningfulness to providers should also be addressed to increase provider engagement in value-based care and quality measurement.

The case for collecting PRMs and reporting PR-PMs is less compelling when providers believe the data to be meaningless or inherently subjective, and providers may feel they are being asked to invest in a process that does not lead to meaningful outcomes. Many providers also only have access to their own data, limiting their ability to benchmark performance for quality improvement. Further, PR-PMs that are used for accountability programs often capture high-level information that is difficult to interpret or translate into action at a patient or provider level. Purchasers may also resist increasing their already significant investments in PRMs if they do not see actionable data or timely improvement in care delivery.

VBP program designers can address these challenges by selecting accountability PRMs and PR-PMs that are actionable for providers. Consistent with the NQF evaluation criteria, measures should be usable for clinical care and quality improvement, in addition to VBP. Payers should share actionable information and data gathered across a spectrum of stakeholders to promote data quality and performance improvement activities. Participants suggested that value-based models, such as the OCM, may be potential vectors for organizing and advancing the development and implementation of meaningful measures. Such models provide a common platform for data sharing and encourage providers to improve the delivery of care.

Implementation Barriers Conclusion

The barriers to successful implementation of PR-PMs in accountability programs are intertwined with the barriers to the development and implementation of PRMs. Ultimately, the roundtable emphasized the need to make gradual changes toward improvement, involving patients during every step of the process.

As one interviewee suggested, **"the patient's voice should be the 'true north.'"**

Measure Gaps and Concepts to Fill Them

Challenges in measure development and barriers to implementation have left gaps in the availability of PR-PMs. Discern drew on several inputs to frame a roundtable discussion on PR-PM gaps and concepts to fill them:

1. Discern's framework outlined 14 domains related to quality of life and experience of care among three phases of care (population at risk, evaluation and initial management, and follow-up care).
2. Discern's measures landscape scan identified goal attainment and care concordance, socioeconomic status, personalized medicine and care planning, caregiver burden, and survivorship (follow-up care phase) as measurement domain gaps.

Figure 14: PRM and PR-PM Gaps Identified During Interviews

Quality of Life	Experience of Care
■ Ability to engage in desired activities	■ Patient reports of provider adherence to clinical guidelines
■ Change and tolerability of symptoms over time	■ Survivorship
■ Financial toxicity and limitations	■ Care coordination and interprovider communication
■ Patient behavior related to treatment and outcomes	■ Goal setting, shared decision-making, care planning
■ Measures of caregiver burden and quality of life, effects on family dynamic	■ Patient expectations for treatment and whether care and outcomes match those expectations

3. The pre-roundtable interviews also discussed perceived PRM and PR-PM gaps in both the quality of life and experience of care categories. Some of the identified gaps included those listed in Figure 14.

These inputs were used to develop a roundtable "pair-share" exercise to identify PR-PM concepts to fill unmet needs. Participants were partnered and assigned one or two of the following domains identified as high-priority in the survey:

- Symptoms and symptom burden
- Physical functional status
- Care coordination
- Access to care

Table 3: Concepts to Fill Unmet Measurement Needs

Priority Domain	Measure Concept
Symptoms and symptom burden, physical functional status	■ Sleep quality ■ Caregiver burden from patient's and own symptoms ■ Physical function and ability to work ■ Symptoms ■ Fatigue ■ Change in functional level
Care coordination	■ Redundant questions/questionnaires and repeated exams
Access to care	■ Affordability/adherence to care ■ Confidence in navigating/accessing the health system
Experience of clinical processes	■ Information regarding specific care processes ■ Initial evaluation after diagnosis ■ Staging complex radiology ■ Multidisciplinary consultations (patient involved) ■ Survivorship program
Goal attainment and care concordance, shared decision-making	■ Appropriate involvement in decision-making process ■ Goals and values considered

- Experience of clinical processes
- Goal attainment and care concordance
- Shared decision-making

Each pair discussed its assigned domain(s) and outlined PR-PM measure concepts that could be used to fill gaps in oncology measures for accountable care programs. Table 3 summarizes the identified concepts by priority domain.

After the pair-share conversations concluded, roundtable participants discussed the generated concepts. Each participant brought different insights on how domains should be prioritized and unique perspectives on what they viewed as gaps. One participant, for example, was particularly concerned that psychosocial PR-PM concepts were not prioritized and suggested the use of distress screening instruments to help measure overall quality of life.

Shared decision-making was another domain that generated lively discussion. Though shared decision-making is often considered a "gold standard" in planning for treatment, participants noted that different patients have different opinions on the appropriate manifestation of shared decision-making. Some patients prefer to make treatment decisions relatively independently, while others may want a physician to provide more input. These varying perspectives must be considered when developing PR-PM concepts related to shared decision-making.

Several of the oncology-related PRMs reviewed by Discern included questions related to the patient's desired level of participation in decision-making. For example, the CAHPS Cancer Care Survey: Shared Decision Making supplemental item asks, "since your cancer was diagnosed, did a doctor or health professional at this cancer center involve you in decisions about your cancer treatment as much as you wanted"[54] A logical extension of the roundtable discussion is that PR-PMs adopted into accountability programs should incorporate similar items as part of the performance measure.

Prioritization of PR-PM Concepts

The roundtable culminated in the prioritization of specific concepts to fill the identified PR-PM gaps for implementation in accountability programs. The responses and discussion regarding concepts generated during the pair-share, along with concepts generated from the interviews and surveys, were summarized and presented to the roundtable participants for a voting exercise. The goal of the exercise was to determine which measure concepts should be the highest priority to create de novo PR-PMs to fill gaps for implementation in VBP programs. Based on participant votes, the top four recommended concepts were:

1. **Symptoms interfered with daily activities**: While symptoms are troubling and unpleasant for patients, this measure concept assesses the functional impact of symptoms. This quality-of-life measure could be used for all three purposes (clinical care, quality improvement, and accountability) and during the evaluation and initial management and follow-up care phases. Physicians, health plans, and practices might be held accountable for this measure, which would encourage providers to perform assessments and offer interventions to help mitigate the impact of symptoms on daily activities.
2. **Symptoms and functioning were collected and conveyed to providers**: This experience-of-care measure concept captures two activities that are critical to ensuring that patients receive care for their symptoms: assessment and communication. For providers to offer the most effective interventions for symptoms, they must collect information from the patient and/or others in the health system and communicate

the interventions back to the patient, closing the feedback loop. This measure could be applied to all three phases of care (population at risk, evaluation and initial management, and follow-up care), and practices, plans, and systems might all be accountable for it.

3. **Provider assessed patients for emotional or social status or concerns and offered referral to treatment**: Though it was not identified as a high-priority domain on the survey, participants recognized the need for measures that encourage providers to help patients meet psychosocial needs and ultimately voted this experience of care concept as one of the top four priorities for PR-PM development. For some providers, intervening in these areas may be more difficult than offering treatment for physical symptoms, and a measure in a VBP program would incentivize conversations and referrals. The level of accountability might be provider-, system-, or health plan-level.
4. **Patient goals and values were considered across the cancer treatment process**: Care concordance with goals, values, and preferences is a foundation of patient-centered care. This concept should be considered across all phases of oncology care and can be used for clinical care, quality improvement, and/or VBP. Physician practices and health systems might be accountable for a PR-PM based on this concept. The underlying PRM could be captured at the beginning of treatment and then at critical pivot points when goals and priorities might change. For pediatric patients, the caregiver may also be given the PRM.

Concepts related to access to care and socioeconomic status were not voted as the highest priority, but in the discussion following the voting exercise, participants emphasized their importance as measure domains that include affordability and financial toxicity.

5. **Access**: Patients often have difficulty affording care, and affordability extends beyond the cost of medications and health care visits to include indirect costs such as missed work, childcare, and transportation. Roundtable participants observed that the access to care concepts included in the voting exercise were too narrowly framed to garner support, and broader measures may have been prioritized higher. The challenge in creating access and affordability PR-PMs may lie in determining which health care entities should be held accountable for performance.
6. **Socioeconomic status**: Some participants expressed surprise that financial toxicity did not emerge as a priority concept. Specialty pharmacies measure socioeconomic status by collecting affordability risk assessments from patients and asking, "How has your cancer diagnosis affected your monthly finances?" One participant noted that the key to assessing patient financial burden is not to focus on its role in overall cost of care, but to treat financial status like a symptom that patients need help managing. Level of accountability is also a concern for this domain.

This early discussion of measure concepts did not attempt to offer detailed PR-PM specifications, but rather to reach consensus on the highest-priority concepts for further development. A full list of the concepts and associated votes generated during the roundtable and by the project team can be found in Appendix VIII.

RECOMMENDATIONS AND CONCLUSIONS

The project participants outlined a strong vision of the future of PRMs and PR-PMs in oncology that suggests the process of developing and implementing measures should meet the following criteria:

- ✓ Include the diverse perspectives of oncology patients and caregivers during every phase of development, implementation, and evaluation
- ✓ Produce meaningful PRMs and PR-PMs that fill current gaps and can be used to meet the complex clinical care, quality improvement, and accountability needs of the oncology space
- ✓ Produce scientifically sound measures
- ✓ Minimize patient and provider burden
- ✓ Support providers in the implementation and use of PRMs and PR-PMs

Based on Discern's landscape scan and gap analysis, along with the results of our participant research, the following strategies and tactics are recommended to help advance this vision. The majority of these are specifically targeted toward policymakers and measure developers.

Strategy 1: Involve patients and caregivers throughout the measurement life cycle to ensure measures capture value

To ensure that PRMs and PR-PMs used for clinical care, quality improvement, and accountability are meaningful to patients and caregivers, measure developers and program designers should involve these key stakeholders at every phase of development, implementation, and evaluation. The diversity inherent in the population of cancer patients necessitates specific efforts to include patients with distinct characteristics related to their conditions and sociodemographic statuses.

Policymaker Action Steps

CMS should offer targeted funding for patient engagement in measure development activities. CMS should also consider including patient involvement in the development process as one of its criteria for selecting PR-PMs for use in programs. Patients and caregivers should also be involved in the design and testing of new payment programs for oncology, including the selection of appropriate measures.

Measure Developer Action Steps

Measure developers should plan forums for engagement in PRM and PR-PM development that include patient-targeted activities and minimize measure science jargon. They could also offer patients incentives for participating to encourage engagement and reduce financial burden, potentially subsidized by CMS or foundation funding. To ensure PRMs include relevant questions and do not add to patient burden, developers should collaborate with providers to collect patient feedback on the administration and content of PRMs both during testing and after implementation.

Other Action Steps

In addition to the regulatory and development action steps, providers can help engage patients in the use

of PRMs by discussing the results of clinically relevant PRMs with their patients, including changes in responses over time.

Strategy 2: Fill care phase and domain gaps in PRMs and PR-PMs

Discern identified many oncology-specific and cross-cutting PRMs in its landscape scan, along with a wide range of cross-cutting PR-PMs. However, only 18 oncology-specific PR-PMs were identified, and only seven PR-PMs are used in CMS accountability programs relevant to oncologists. Additionally, gaps exist in the available measures in the population at risk and follow-up care (survivorship) phases of care, as well as in these measure domains: goal attainment and care concordance, socioeconomic status, personalized medicine and care planning, psychosocial status, clinical processes, patient engagement level, and caregiver engagement and burden. Recommended action steps for filling these gaps are as follows:

Policymaker Action Steps

Following the priorities outlined in the survey, CMS program designers should include PR-PMs for care coordination, symptoms and symptom burden, and access to care in future versions of programs (such as the OCM). CMS can explore the use of existing cross-cutting PR-PMs when oncology PR-PMs are not available, but they should be validated with an oncology population before implementation.

Because Medicare is the largest single payer of oncology services, CMS effectively sets the priorities for measure development across the oncology space.[55] CMS should focus on PRM and PR-PM development priorities related to filling care phase and domain gaps by offering funding, such as the MACRA funding opportunity described earlier. CMS should also include these areas as priorities in its Meaningful Measures and other initiatives.

CMS serves as the steward for many measures in its VBP programs. For example, CMS serves as the steward for five of the measures in the OCM and six of the measures in the PCHQR program. CMS should consider stewarding PR-PMs in gap areas for inclusion in current and future programs.

Measure Developer Action Steps

To ensure PRMs and PR-PMs are available for clinical care, quality improvement, and accountability, developers should work to fill priority gap areas as

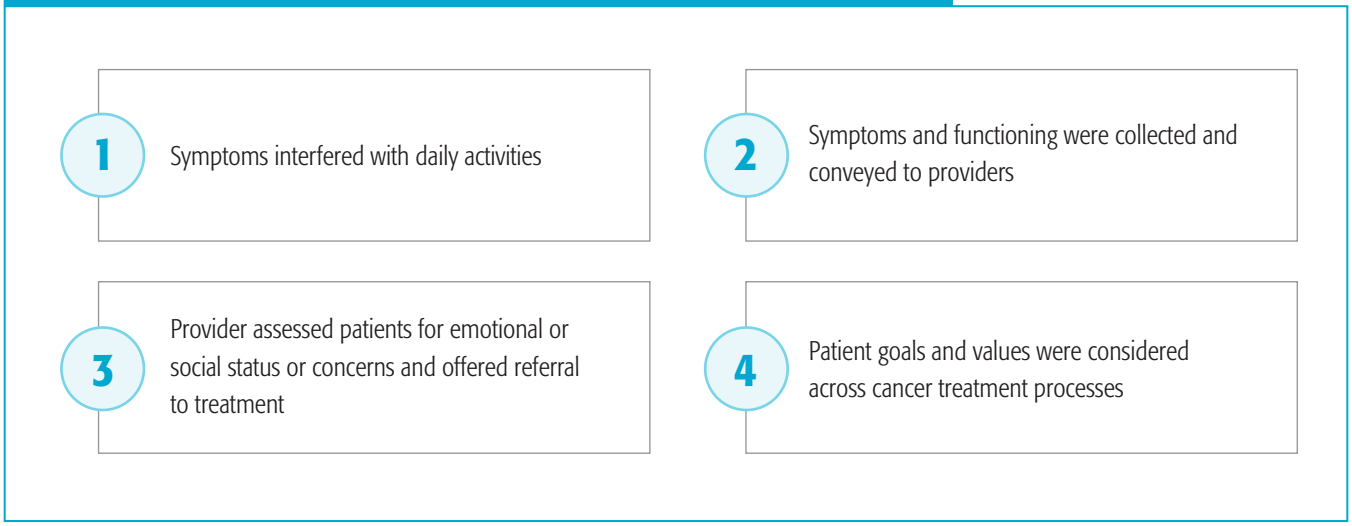
Figure 15: Recommendations for Filling Gaps in PR-PMs and PRMs

- Create PR-PMs to capture patient health and experience during the population at risk phase of care, address survivorship during the follow-up-care phase, and fill domain gaps in the evaluation and initial management phase.
- Enhance PRMs and create PR-PMs to fill gaps in the domains of goal attainment and care concordance, socioeconomic status, and personalized medicine and care planning.
- Build on existing oncology-specific PRMs that capture psychological status to create additional PR-PMs in that domain.
- Leverage cross-cutting PRMs that focus on patient experience of clinical processes as sources to develop oncology-specific PR-PMs in that domain.
- Develop PRMs and PR-PMs that assess the patient engagement level as well as caregiver engagement and burden.

shown in Figure 15.

To develop PR-PMs for inclusion in accountability programs, developers should focus efforts on specific measure concepts prioritized by the roundtable (Figure 16). Some of these PR-PMs may be supported by questions available in current PRMs identified as "promising" by participants. For example, "Symptoms interfered with daily activities" could be built from the PROMIS Bank v1.1—Pain Interference item: "How much did pain interfere with your day to day activities?" or from one of several items on the PRO-CTCAE that ask, "In the last 7 days, how much did [symptom] interfere with your daily activities?"[56]

Figure 16: Prioritized Measure Concepts for Accountability Programs



Other priority domains for PR-PM concept development specific to accountability were access to care and socioeconomic status (financial toxicity). The roundtable did not reach consensus on specific concepts in these domains but emphasized the importance of selecting the appropriate level of accountability. For example, a health plan or accountable care organization (ACO) might be an appropriate level of accountability for measures related to financial toxicity due to its ability to help patients improve financial "symptoms" by covering or offering additional services.

Strategy 3: Address methodological challenges

Because of their reliance on PRM data sources, PR-PMs are subject to specific methodological challenges, including those related to measure validity and reliability. Some of these challenges may be addressed as follows:

Policymaker Action Steps

Because of the potential influence on provider behavior and payment, CMS should select PR-PMs used for VBP programs that meet high standards of scientific rigor. To address bias related to small denominators, CMS program designers should look for ways to increase the scale of the population being measured, like including cross-cutting PR-PMs, choosing PR-PMs with a group or system level of accountability, or combining data from multiple years or payers. Finally, CMS should continue to offer funding opportunities to support the development and evaluation of meaningful, methodologically sound, and fit-for-purpose PRMs and PR-PMs.

Measure Developer Action Steps

Developers should consider the purpose of each PRM and PR-PM during development. Some measures may be applicable for multiple populations and uses, but some are only appropriate for a specific application.

Appropriate risk adjustment is needed to avoid negative impacts on providers that serve populations associated with lower PRM response rates or poor performance

on PR-PMs. In designing risk adjustment, developers should consider the added complexity that the diverse population of cancer patients may introduce.

Other Action Steps

Generating enough data to evaluate the use of PRMs and PR-PMs across diverse populations is a process that can be supported by life sciences companies. As PRMs are tested and used to evaluate programs and products, life sciences companies should share PRM results more broadly or contribute them to a national database to support future research.

Strategy 4: Reduce provider and patient burden by standardizing PRMs and PR-PMs

As more accountability programs require the use of PR-PMs and the use of these programs expands, a lack of alignment around the measures used can lead to or increase provider and patient burden as providers administer multiple PRMs and patients are asked to complete multiple or lengthy PRMs. Policymakers and measure developers should align around a small number of standardized PRMs that are valid, reliable, and comprehensive.

Policymaker Action Steps

CMS should choose standard PR-PMs and/or PR-PMs built from standard PRMs for use across multiple programs. It should also select PR-PMs based on PRMs that are useful in clinical care and quality improvement in addition to accountability so that providers can use the same instruments for multiple purposes.

To ensure the availability of appropriate PRMs, CMS should fund the enhancement of current tools to create a core set of standardized PRMs that can fill gaps as described above and supply data elements to support other PR-PMs used in accountability programs. The resulting PRMs and data elements should be published as specifications for health information technology (HIT) vendors to build into EHRs.

Measure Developer Action Steps

Developers should create PR-PMs from items available in existing PRMs wherever possible. To streamline administration and fill gaps, developers should work to create a very small core set of standardized instruments. Wherever possible, developers should build on or include existing items from validated tools such as the PROMIS tool and the PRO-CTCAE.

Standardized PRMs should be adaptable and fit for multiple purposes. They should also capture variation in patient needs (e.g., context, characteristics, abilities), goals, and preferences to support risk adjustment. To reduce patient burden, PRM developers should eliminate any questions that are not useful or meaningful and build in skip patterns so HIT vendors can use technology to automatically skip irrelevant questions.

Strategy 5: Support providers in PRM and PR-PM implementation

A lack of provider resources and insufficient incentives inhibit provider adoption, use, and success with PRMs and PR-PMs. Policymakers and payers can support providers in the implementation and use of PRMs and PR-PMs as follows:

Policymaker/Payer Action Steps

CMS and other program administrators (such as health plans) should use a stepwise approach to program implementation that incorporates evaluation and learning at every step:

1. When new accountability programs are

introduced, offer incentives to help providers fund the initial implementation of PRMs in provider organizations. Subsidize resources needed to administer PRMs, such as improved technology. For example, CMS might offer a free, standardized platform for collecting oncology PRMs that allows providers to submit results. Likewise, CMS could incentivize EHR vendors to develop common PRM(s) in their platforms and facilitate interoperability with any CMS platforms for data submission.

2. Set realistic expectations for implementation and performance by including validated thresholds that providers can use as benchmarks or targets. Share best practices in PRM administration and data collection to help ensure that PR-PMs accurately reflect actual performance.
3. Build in time for providers and programs to gather and analyze data, possibly during a pay-for-reporting period.
4. Calibrate approaches to improve program structure, PRMs, and PR-PMs based on lessons learned through feedback loops that allow program designers and measure developers to learn from providers and patients using the PR-PMs and PRMs.
5. Give providers time and information to improve both PRM administration and performance toward the PR-PMs. This could include identifying key performance indicators from the PRMs that correlate with overall performance on PR-PMs and listing suggested interventions around those measures.
6. Institute pay-for-performance and begin evaluating additional PR-PMs.

Measure Developer Action Steps

Measure developers could offer guidance for implementation of their PRMs and PR-PMs, including best practices in data collection, supportive documentation, and links to quality improvement resources. This guidance could be shared with CMS, directly with health plans, or posted on developer websites in a provider resources section.

Conclusion: Elevate the Patient Voice While Avoiding Unintended Consequences

Policymakers, measure developers, and other stakeholders are working to increase the use of PR-PMs in accountability programs for oncology, but face the potential for unintended consequences.

Implementing PR-PMs carries the risk of creating patient and provider burden or incentivizing behaviors and outcomes that are not meaningful or do not accurately reflect quality of care. Program designers and implementers should be aware of these risks and take steps to avoid or mitigate them by involving patients throughout the phases of measure development and program design, offering appropriate incentives for provider implementation, and ensuring that development methodology considers the complexity and variety of cancer patients and treatment.

The implementation of VBP programs may have unintended consequences especially relevant for PR-PM use. As noted in NPC and Discern Health's 2017 white paper, misaligned incentives could lead to a decrease in the use of costly but effective treatment or avoidance in treating the highest-cost, highest-need patients, especially patients with lower socioeconomic status.[57]

Quality measures serve as the brakes on unrestrained cost-cutting, especially in population health payment models, and including PR-PMs that are methodologically sound and meaningful to patients in VBP models can help guard against these unintended consequences.

APPENDIX I: FRAMEWORK DEFINITIONS FOR CATEGORIES AND DOMAINS

Quality of Life Category

This general category refers to "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns," following the World Health Organization definition.[58] It is a broad-ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, and relationships to salient features of their environment. For the purposes of this project, the following domains fit within the quality of life category:

- **Symptoms and symptom burden**: Perception or assessment of disease symptoms (e.g., pain, fatigue, dyspnea).[59]
- **Physical functional status**: "Ability to physically perform normal daily activities required to meet basic needs, fulfill usual roles, and maintain health and well-being"[60,61]
- **Socioeconomic status**: Factors related to social standing or "class," such as education, income, and occupation. These factors might include financial instability and financial toxicity/burden of cost.[62]
- **Psychosocial and cognitive status**: Interrelation of social factors and individual thought and behavior, including feelings about the self and relationships; the state of cognitive processes; assessment of mood; emotional well-being or distress; and expression of religious or spiritual feelings.[63]
- **Health behaviors/self-management**: Behaviors expressed by individuals to protect, maintain, and/or promote their health status, including day-to-day management of an illness.[64]

Experience of Care Category

According to AHRQ, "[t]o assess patient experience, one must find out from patients whether something that should happen in a health care setting … actually happened or how often it happened."[65] While AHRQ also stated that "the terms patient satisfaction and patient experience are often used interchangeably, but they are not the same thing," following Discern and NPC's 2017 paper, we classify patient satisfaction as a subcategory of patient experience.[66] This is consistent with many of the definitions outlined by other researchers. For example, the Beryl Institute defines patient experience as "the sum of all interactions, shaped by an organization's culture, that influence patient perceptions, across the continuum of care."[67] The following domains fit within the experience of care category:

- **Experience of clinical processes**: whether clinicians performed or administered specific clinical care processes;[68]
- **Satisfaction**: whether expectations about a health encounter were met;[69]
- **Access to care**: ability to gain entry to the health system or sites of care, find providers to meet patient needs, and receive needed services;[70]
- **Care coordination**: experience of providers organizing patient care activities, communicating, and transferring information within and across care participants;[71]

- **Personalized medicine and care planning**: involving the use of an individual's specific health information to develop a treatment plan.[72] Care planning is the process by which the individual's specific needs are also considered to achieve goals and outcomes;[73]
- **Goal attainment and care concordance**: alignment of health care services and outcomes with expressed goals and preferences;[74]
- **Engagement and activation**: an individual's involvement in their health care and the practices providers use to promote that involvement;[75,76,77,78,]
- **Shared decision-making**: process of communication in which clinicians and patients work together to make optimal health care decisions that align with what matters most to patients;[79] and
- **Caregiver-reported measures**: Any measures where the person completing the PRM is a caregiver, such as a family member, not a provider or patient.[80]

APPENDIX II: KEY SOURCES CONSULTED IN PRM LITERATURE REVIEW

PRM Sources Consulted

- American Institutes for Research
- American Society of Clinical Oncology
- CMS technical expert panel calls
- Consumer Assessment of Healthcare Providers and Systems
- European Society for Medical Oncology
- Healthcare Effectiveness Data and Information Set
- Institute for Clinical and Economic Review
- International Consortium for Health Outcomes Measurement Standard Sets
- International Society for Pharmacoeconomics and Outcomes Research
- International Society for Quality of Life Research
- MN Community Measurement
- National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology
- Patient-Centered Outcomes Research Institute
- Patient-Centered Primary Care Collaborative
- Patient-Reported Outcomes Measurement Information System
- PatientsLikeMe
- Physician Consortium for Performance Improvement (PCPI) inventory of patient engagement PROMs
- RTI International
- "The Voice of the Patient"

APPENDIX III: LIST OF IDENTIFIED ONCOLOGY-RELATED PRMS AND PR-PMS

PRM	PR-PM	Steward	CMS Program Use
CAHPS for ACOs	Shared decision-making process (NQF #2962)	Massachusetts General Hospital	MSSP
Cancer QPI Communication Measurement Tool	Excellent communication from health care professionals throughout cancer care	NHS Scotland	OCM Performance Multiplier
Cancer QPI Shared Decision-Making Measurement Tool	Enabled by health care professionals to share decisions about care	NHS Scotland	
EPIC-CP, EPIC-26, or EPIC-46 Localized Prostate Cancer	Bowel function	The University of Texas MD Anderson Cancer Center	
	Sexual function	The University of Texas MD Anderson Cancer Center	MIPS QCDR
	Urinary frequency, obstruction, and/or irritation	The University of Texas MD Anderson Cancer Center	MIPS QCDR
	Urinary incontinence	The University of Texas MD Anderson Cancer Center	
	Vitality	The University of Texas MD Anderson Cancer Center	
"Standard instrument." Ex: Faces Pain Rating, Brief Pain Inventory	Oncology: Medical and Radiation – Pain Intensity Quantified (NQF #0384e, has a PRM component, not coded as PR-PM)	PCPI	Hospital Compare; PCHQR; OCM

PRM	PR-PM	Steward	CMS Program Use
"Standardized depression screening tool." Ex: PHQ-9	Preventive Care and Screening: Screening for Depression and Follow-Up Plan (NQF #0418, has a PRM component, not coded as PR-PM)	CMS	MSSP; MIPS; Physician Compare; OCM
FACT-B, FACT-L	Composite quality of life from FACT-B (breast cancer) (NQF Review #OT2-017-09, not endorsed)	Functional Assessment of Chronic Illness Therapy (FACIT)	
	Composite quality of life from FACT-L (lung cancer) (NQF Review #OT2-016-09, not endorsed)	FACIT	
FAMCARE Patient Scale	Advanced cancer outpatient experiences: overall satisfaction score	University Health Network	
Patient-Reported Experience of Care Survey (based on Cancer CAHPS)	Patient-reported experience of care composite	AHRQ	OCM
PRO-CTCAE	Constipation symptom control during chemotherapy	MN Community Measurement	
	Nausea symptom control during chemotherapy	MN Community Measurement	
	Pain symptom control during chemotherapy	MN Community Measurement	
QHP Enrollee Survey	Communicated procedure outcomes following an interventional oncology procedure	Society of Interventional Radiology	

PRM	PR-PM	Steward	CMS Program Use
Not specified	Patient-reported assessment of communication and shared decision-making for interventional oncology procedures	Society of Interventional Radiology	
PROMIS SFv1.0 6a Fatigue or Brief Fatigue Inventory	Fatigue improvement	Oncology Nursing Society	MIPS QCDR

APPENDIX IV: ROUNDTABLE LEADERS AND PARTICIPANTS

Participant	Affiliation
Roundtable Co-chairs	
Mark McClellan	Duke-Margolis Center for Health Policy
Ethan Basch	UNC Lineberger Comprehensive Cancer Center
Project Sponsors and Staff	
Kimberly Westrich	National Pharmaceutical Council
Taruja Karmarkar	National Pharmaceutical Council
Tom Valuck	Discern Health
Theresa Schmidt	Discern Health
Brittany Perkins	Discern Health
Palak Patel	Discern Health
Roundtable and Interview Participants	
Joseph Alvarnas (interview only)	City of Hope
Andrew Baskin	Aetna
John Bernot (roundtable only)	National Quality Forum
Rachel Brodie	Pacific Business Group on Health
W. Garth Callaghan	Patient representative (Napkin Notes Dad)
Andrea Ferris (roundtable only)	LUNGevity
Karen Fields	Moffitt Cancer Center
C. Lyn Fitzgerald	National Comprehensive Cancer Network

Participant	Affiliation
Jennifer Griggs	American Society of Clinical Oncology (representative)
Cynthia Grossman	FasterCures
Linda House (interview only)	Cancer Support Community
Roxanne Jensen	National Cancer Institute
Paul Kluetz	Oncology Center of Excellence, U.S. Food and Drug Administration
Jeremy Nobel	Harvard Medical School, formerly of the Northeast Business Group on Health
Stacey Moser	Patient representative (The Leukemia and Lymphoma Society)
Sally Okun	PatientsLikeMe
Collette Pitzen	MN Community Measurement
Kristen Santiago (roundtable only)	Cancer Support Community
Ann Steagall (roundtable only)	Biologics, Inc.
Katherine Szarama	Center for Clinical Standards and Quality, CMS
Manasi Tirodkar (roundtable only)	National Committee for Quality Assurance
Andrew York (roundtable only)	Center for Medicare & Medicaid Innovation, CMS
Ashley Wilder-Smith (interview only)	National Cancer Institute
Emily Wilson (roundtable only)	American Society for Radiation Oncology
Yousuf Zafar	Duke Cancer Institute

APPENDIX V: SUBJECT MATTER EXPERT INTERVIEW DISCUSSION GUIDE[iv]

Goals for Interview

Our goals for this interview are to (1) increase our understanding of how PROMs and PRO-PMs are currently being used, (2) gain your perspective on the challenges that are limiting wider use of PROMs and PRO-PMs, and (3) identify strategies that could be implemented to address these challenges and expand use of PROMs and PRO-PMs. This is a background interview; we will not be attributing quotes or opinions to you.

Interview Questions

Below is a sampling of high-level questions that we will ask during the interview. Additional, more detailed questions will be asked based on your expertise and perspective. For example, we will ask some experts for more specific thoughts regarding measure development methodology or to comment on the use of PROMs across the product lifecycle. We will also ask follow-up questions throughout the interview.

1. **PROs work**. Please describe your work, or the work of your organization, related to PROs in oncology.
2. **PROMs gaps**. What do you see as the most critical gaps in existing oncology PROMs? Are there aspects of oncology care that are being missed by existing PROMs? What are the barriers to additional development of oncology PROMs?
3. **PROM patient burden**. Patient burden and survey fatigue are widely recognized as significant barriers to the use of PROMs. This issue will only become more challenging as PROs become more widely used. What are some practical actions that could be taken to reduce patient burden?
4. **PROM provider concerns**. Providers have voiced skepticism on the value of wider use of PROMs in clinical practice, specifically on the required resources for PROM administration and analysis and concern that patients are less objective than their own assessments. What are some ways to address these concerns? What are some ways to incentivize provider adoption of PROMs?
5. **PROM validation for additional populations**. We often see that PROMs are developed and validated for one patient population (e.g., a certain condition), and are then utilized for other populations without being re-validated. How significant of a problem is this in your perspective? What are some practical strategies for building on existing measures to create PROMs for additional populations or settings?
6. **PRO-PM development**. Few PROMs are developed into PRO-PMs and the process is not well defined. What are the most critical factors preventing wider PRO-PM development? Methodological difficulties? Lack of development resources? Not enough interest in using them? What does a "best practice" development methodology include?

iv When the Discussion Guide was developed, the Discern team used the terms "PROM" and "PRO-PM" for consistency with common nomenclature, but specified that we were not restricting our analysis or questions to purely outcomes measures. This terminology was later changed to "PRM" and "PR-PM" for accuracy and to avoid confusion.

7. **PRO-PM critical gaps**. While there is a desire for more PRO-PMs, we cannot expect all measure gaps to be filled in the short term. What do you see as the most important measure domains (e.g., quality of life, functional status) for near-term oncology PRO-PM development? What types of measures would you prioritize?
8. **PROMs and PRO-PMs for care concordance**. We have heard that alignment of care with patient goals is a critical gap. Do you agree? If so, how would you ideally structure a PROM and PRO-PM to ascertain whether care was aligned with patient goals?
9. **PRO-PMs in value-based payment**. In a value-based care environment, what is the best use of PRO-PMs? Is it fair and appropriate to hold providers financially accountable for PRO-PM results, for instance, in a model like the Oncology Care Model?

APPENDIX VI: ROUNDTABLE AGENDA

Time	Agenda Item
8:30 – 8:45	**Gathering and continental breakfast**
8:45 – 9:15	1. Welcome, objectives, and introductions
9:15 – 10:00	2. Patient panel
10:00 – 10:30	3. Framework and gap analysis: findings and implications
10:30 – 10:40	**Break**
10:40 – 11:30	4. Group discussion: defining the key issues and unmet needs in PRMs and PR-PMs for oncology
11:30 – 12:00	5. Pair-share: identifying measure concepts to fill unmet needs
12:00 – 12:30	6. Pair-share: report outs and group discussion
12:30 – 12:45	7. Summary of morning discussion
12:45 – 1:00	**Break for lunch**
1:00 – 1:45	8. Breakout sessions: generating solutions for priority issues
1:45 – 2:30	9. Breakout sessions: report outs and discussion
2:30 – 2:45	10. Prioritizing measure concepts and solutions
2:45 – 3:00	11. Discuss results of prioritization exercise
3:00 – 3:30	12. Synthesis, next steps, wrap-up, and adjourn

APPENDIX VII: DESCRIPTIONS OF CMS VBP PROGRAMS WITH ONCOLOGY-SPECIFIC PR-PMS

PPS-Exempt Cancer Hospital Quality Reporting (PCHQR) Program

The PCHQR program is a pay-for-reporting program that requires participating hospitals to submit certain quality measures to support best practices within their facilities.[81]

Oncology Care Model (OCM)

The OCM is a specialty model developed by the Center for Medicare and Medicaid Innovation to test a VBP approach in which physician practices are held accountable for cost and quality in episodes of care surrounding chemotherapy administration to cancer patients.[82] One PR-PM and two provider-reported measures with PRM components are included in the OCM. All three of these measures will be subject to pay-for-performance in 2019. The Patient-reported Experience of Care measure is a PR-PM calculated from a multi-item survey, with five scored components based on the Cancer CAHPS Survey: overall rating exchanging information with patients, access, enabling self-management, and effective communication. A shared decision-making component is reported, but not scored for the OCM.

Merit-based Incentive Payment System (MIPS)

The MIPS program is one of the two pathways offered through CMS' Quality Payment Program (QPP). Through this pay-for-performance program, providers report on measures related to four different performance categories: quality, promoting interoperability, improvement activities, and cost.[83] MIPS QCDRs may include measures outside of the QPP that have been approved by CMS for use in the accountability program.[84]

Medicare Shared Savings Program (MSSP)

The MSSP is a CMS payment program that allows providers to create ACOs and assume financial risk for their performance on metrics of cost and quality.[85] Providers participating in ACOs may share in earned savings and avoid maximum losses only if they report quality measures data to CMS on an annual basis and meet established performance standards. The four domains of MSSP quality measures are patient/caregiver experience, care coordination/patient safety, preventive health, and at-risk populations. One of the 31 MSSP measures is a shared decision-making PR-PM sourced from CAHPS for ACOs. This PR-PM specifies cancer patients receiving radical prostatectomy and mastectomy among the target populations in its denominator. Another MSSP measure for depression is clinician-reported, but includes a PRM component.[86]

APPENDIX VIII: RESULTS OF VOTING EXERCISE

Measure Concept	Votes
Symptoms and symptom burden/physical functional status	
■ Process: Symptom PROs collected and conveyed to providers	25 points
■ Function collected and conveyed to doctor	25 points
■ Symptoms interfered with ability to perform daily activities and roles	20 points
■ Pain brought to comfortable level within set period after reporting	17 points
■ Change in level of fatigue following treatment (also consider pain, nausea, vomiting, and dyspnea)	8 points
■ Caregiver symptom burden assessment and management	5 points
■ Process: Did provider go over PRO results in clinic visit?	5 points
■ Missed work in past 30 days due to symptoms	0 points
■ Time under baseline function	0 points
Access to Care	
■ Ability to afford treatment	11 points
■ Provider discussed options and benefits of palliative and end-of-life services	9 points
■ Confidence in navigating/accessing the health system	6 points
■ Patients able to get needed appointments in a timely fashion	5 points
■ Patients received referrals to specialists in a timely fashion	2 points
Care Coordination	
■ Clinicians seemed informed and up-to-date about care from other providers	6 points
■ Redundancy in information requested and/or tests performed across providers	4 points
■ Patients received assistance from care team to manage care, tests, or treatment from different providers	3 points
■ Provider's office reminded patients about tests, treatments, appointments between visits	0 points

Measure Concept	Votes
Clinical Processes	
■ Provider assessed patients for emotional or social status or concerns and offered referral to treatment	20 points
■ Treatment effects corresponded with what providers told patient to expect	10 points
■ Patients felt adequately prepared to manage effects of treatment	8 points
■ Adequate information into post-treatment program options for survivors	8 points
■ Patient understanding of diagnostic and staging process (retrospective)	3 points
■ Provider offered counseling for fertility preservation	1 point
Goal attainment and care concordance	
■ Patient goals and values were considered across the cancer journey	16 points
■ Patient goals and values were considered during the treatment planning process	14 points
■ Addressing how the patient would like to make the decision	3 points
■ Provider respected patient decision to discontinue treatment	3 points
■ Patients able to return to work as soon as planned	1 point

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