Improving patient-reported measures in oncology: a payer call to action

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SUMMARY

Despite rising interest in integrating the patient voice in value-based payment (VBP) models for oncology, barriers persist to implementing patient-reported measures (PRMs), including patient-reported performance measures (PR-PMs). This article describes the landscape of oncology PRMs and PR-PMs, identifies implementation barriers, and recommends solutions for public and private payers to accelerate the appropriate use of PRMs in oncology VBP programs.

Our research used a multimethod approach that included a literature review, landscape scan, stakeholder interviews and survey, and a multistakeholder roundtable. The literature review and landscape scan found that limited oncology-specific PR-PMs are available and some are already used in VBP programs. Diverse stakeholder perspectives provided insight into filling current gaps in measurement and removing implementation barriers, such as limited relevance of existing PRMs and PR-PMs for oncology; methodological challenges; patient burden and survey fatigue; and provider burden from resource constraints, competing priorities, and insufficient incentives. Key recommendations include: (a) identify or develop meaningful measures that fill gaps, engaging patients throughout measure and program development and evaluation; (b) design programs that include scientifically sound measures standardized to reduce patient and provider burden while supporting care; and (c) engage providers using a stepwise approach that offers resources and incentives to support implementation.

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The transition from fee-for-service to value-based payment (VBP) drives quality improvement and cost reduction.[1] To ensure VBP programs consider how patients and family caregivers define "high-value" care, stakeholders have advanced the use of quality measures that assess and amplify patient perspectives.[2] Integrating patient voices in VBP is particularly relevant for oncology, where patients are challenged by high symptom burden, psychologic and financial stress, and complicated care pathways. However, incorporating patient perspectives is undermined by barriers, which this paper explores in detail, to implementing meaningful, methodologically sound patient-reported measures (PRMs) and patient-reported performance measures (PR-PMs). PRMs are tools that directly capture patients' perceptions of their experiences and outcomes, whereas PR-PMs are measures built from these tools that capture performance related to these experiences and outcomes over time.

Payers play a substantial role in measuring and incentivizing health care quality. For patient perspectives to be successfully integrated into VBP, payers must drive and support implementation of PRMs and PR-PMs as described below. Payers also benefit from implementation in several ways:

- Patient and physician perceptions of care outcomes and experience often differ, so understanding patient perspectives supports identification of, and payment for, more effective interventions, while promoting patient-centered care.[3]
- PRMs can help payers understand risks and trends at the population level by identifying individuals in need

of care management and helping providers respond to symptoms earlier.[4]

- Encouraging providers to collect and use PRMs can improve patient outcomes and reduce costs. PRMs have been associated with improved survival, quality of life, and symptom management in oncology.[4-6] Poorly controlled symptoms and related patient suffering are a common driver of emergency room (ER) visits and hospital admissions.[6] One study found that 53% of ER visits by oncology patients could have been prevented with proper symptom management, saving a median $1,047 per preventable visit.[7]

Elsewhere, we have described 3 key uses of PRMs and PR-PMs in oncology: enhancing clinical care at the provider level by giving providers information for decisions and facilitating communication; driving and measuring quality improvement at the provider and system levels; and assessing performance for accountability purposes (including VBP) at the provider, system, and population levels.[8] This paper focuses on the VBP context and describes the landscape of PRM and PR-PM use, barriers to implementation, and actions tailored to payers to advance appropriate use of these measures.

Methods

Our analysis used a multimethod approach, including a literature review and landscape scan, stakeholder interviews and survey, and a roundtable meeting.

We guided our landscape scan by developing a framework for identifying and describing PRMs and PR-PMs, beginning with selecting these terms. Patient-reported outcome measures (PROMs) are tools that capture direct reports from patients about their care outcomes.[9] Patient-reported outcome performance measures (PRO-PMs) are measures constructed from PROMs that assess performance on outcomes over time.[10] We expanded on these concepts by using the terms "PRM" and "PR-PM" to emphasize the need to assess patient-reported facets of care and experience beyond clinical outcomes. These include access to care, shared decision making, and patient engagement or education. "PRM" is a commonly used term, although not as common as "PROM", but a search of PubMed revealed no results for the terms "patient-reported performance measure" or "PR-PM."

Our framework includes 3 care phase domains that build on the National Quality Forum (NQF)'s Patient-Focused Episode of Care Model for Cancer and were validated using the National Voluntary Consensus Standards for Quality of Cancer Care.[11,12] It also includes 14 content domains related to quality of life and experience of care that were derived

from comparing and contrasting several other measurement frameworks and modified to better describe the measures identified in the landscape scan.[13-16]
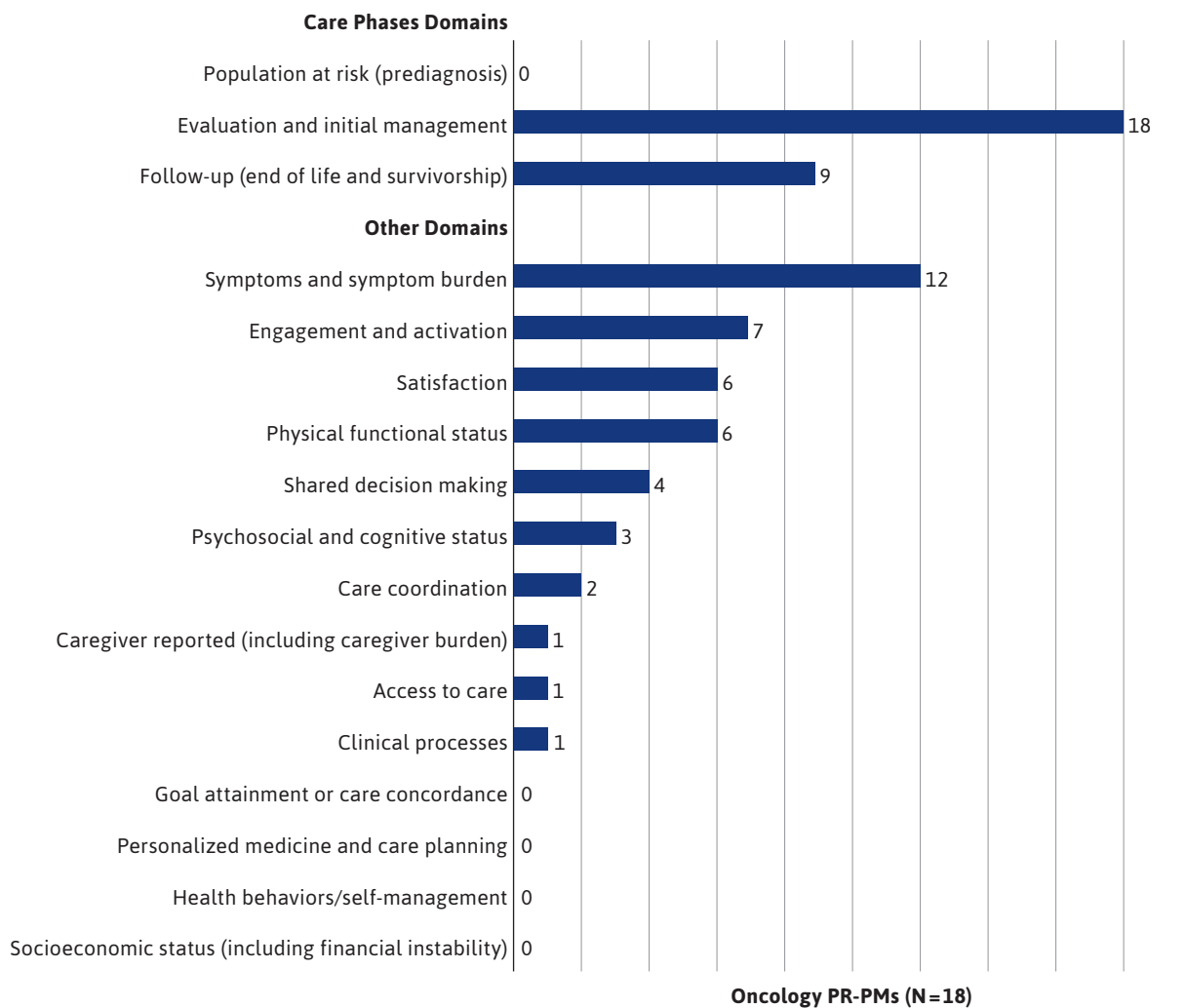
We used the NQF Quality Positioning System (QPS), Agency for Healthcare Research and Quality (AHRQ) National Quality Measures Clearinghouse (NQMC), Centers for Medicare & Medicaid Services (CMS) Quality Measures Inventory, and gray literature to identify the availability of PRMs and PR-PMs. To ensure we included the most recent information, we also visited the websites of public-facing oncology-related accountability programs known to the industry and identified in previous work, including VBP programs, to identify PRMs and PR-PMs included in those measure sets. The initial scan captured PR-PMs available as of April 2018; we updated the oncology VBP program measure scan in May 2020. (The NQMC was removed from the AHRQ website in July 2018. Measures included in the landscape scan were collected and assessed before that.)

The landscape scan informed 17 interviews with 18 stakeholders (1 interview had 2 people) in oncology, quality measurement, and VBP to gain perspectives about development and use of PRMs and PR-PMs in oncology VBP. These semistructured interviews were conducted on the telephone with one primary interviewer and a secondary notetaker. Ahead of the interview, each interviewee was given a discussion guide, which served as the backbone of the conversation while allowing flexibility. Additionally, we administered a brief survey via Survey Monkey to interviewees and roundtable convening invitees. The survey had 15 questions, including a mix of multiple choice and open-ended response options. We received 18 responses, which informed the roundtable discussion.

Twenty-four experts participated in the September 2018 roundtable. We selected participants with previous experience working with PRMs, performance measures, oncology research, and/or oncology patients. These experts offered insight from oncology care, regulatory/policy, quality measurement, employer purchasing, academic research, health insurance, and patient experience. In addition to patient advocacy organizations, the roundtable also included an oncology patient receiving active treatment and a cancer survivor. The highly interactive 1-day roundtable began with a patient panel and included a review of the landscape and survey findings, guided group discussions, round-robin sharing, and dot voting. The roundtable dialogue informed our recommendations for filling gaps in oncology PRMs and PR-PMs and removing barriers to implementation that impact patients, providers, and payers in oncology VBP programs.

Two patients participated in this project as subject matter experts. The research was not covered by the U.S.

FIGURE 1   Oncology PR-PMs per Domain[a]

Care Phases Domains

Domain	Count
Population at risk (prediagnosis)	0
Evaluation and initial management	18
Follow-up (end of life and survivorship)	9

Other Domains

Domain	Count
Symptoms and symptom burden	12
Engagement and activation	7
Satisfaction	6
Physical functional status	6
Shared decision making	4
Psychosocial and cognitive status	3
Care coordination	2
Caregiver reported (including caregiver burden)	1
Access to care	1
Clinical processes	1
Goal attainment or care concordance	0
Personalized medicine and care planning	0
Health behaviors/self-management	0
Socioeconomic status (including financial instability)	0

Oncology PR-PMs (N=18)

[a]Some PR-PMs capture multiple domains.
PR-PM = patient-reported performance measure.

Department of Health and Human Services regulations for Activity Human Subjects Research and did not require institutional review board approval.

Results

AVAILABILITY OF PRMS AND PR-PMS

The landscape scan identified a universe of more than 800 PR-PMs, including 515 crosscutting measures applicable to oncology and 18 oncology-specific PR-PMs. These findings illustrate that, although a large pool of PR-PMs is available, very few are specific to oncology. However, some of the many crosscutting PR-PMs might be considered for inclusion in an oncology VBP program if they capture concepts that are meaningful to patients, are relevant to the program, and can be tested in the program population. We also identified 106 oncology-specific PRMs and 155 crosscutting PRMs. Not all PRMs were associated with PR-PMs, and some of the oncology-specific PR-PMs are based on crosscutting PRMs.

Figure 1 shows the distribution of PR-PMs across measure domains, with some falling into multiple domains.

TABLE 1	PRMs and PR-PMs in CMS Oncology VBP Programs (Updated May 2020)	
Program	**PR-PM**	**Note**
PCHQR[45]	PCH-16 (NQF 0384): Oncology: medical and radiation—pain intensity quantified	Process measure: Not a PR-PM, but component "pain intensity quantified" indicates the presence of pain through use of a PRM
	PCH-29 (NQF 0166): HCAHPS Survey • Communication with doctors • Communication with nurses • Responsiveness of hospital staff • Communication about medicines • Discharge information • How well patients understood the care they would need after leaving the hospital • Cleanliness of the hospital environment • Quietness of the hospital environment • Overall rating of the hospital • Recommendation of the hospital	An 11th measure related to pain control was removed per the 2020 Hospital Inpatient Prospective Payment Systems Final Rule to address concerns related to opioid prescribing
OCM[46,47]	OCM-4a (NQF 0384): Oncology: medical and radiation—pain intensity quantified	Process measure: Not a PR-PM, but component "pain intensity quantified" indicates the presence of pain through use of a PRM
	OCM-5 (NQF 0418): Preventive care and screening for depression and follow-up	Process measure: Not a PR-PM, but provider screening of patients uses a PRM and subsequent care planning if screened positive[48]
	OCM-6: Patient-reported experience of care	Patient-reported experience measure
MIPS General Oncology Measure Set[49]	MIPS 0384e (NQF 0384): Oncology: medical and radiation—pain intensity quantified	Process measure: Not a PR-PM, but component "pain intensity quantified" indicates the presence of pain through use of a PRM
MIPS Radiation Oncology Measure Set[50]	MIPS 0384e (NQF 0384): Oncology: medical and radiation—pain intensity quantified	Process measure: Not a PR-PM, but component "pain intensity quantified" indicates the presence of pain through use of a PRM
Oncology-specific MIPS QCDRs[51]	ONSQIR21: Patient-reported HRQOL during treatment for advanced cancer	PRO-PM
	PIMSH4: Oncology: patient-reported pain improvement	PRO-PM

[a]Four oncology-specific PR-PMs were removed from MIPS QCDRs in 2020.
HCAHPS = Hospital Consumer Assessment of Healthcare Providers and Systems; HRQOL = health-related quality of life; MIPS = Merit-Based Incentive Payment System; NQF = National Quality Forum; OCM = Oncology Care Model; PCHQR = Prospective Payment System-Exempt Cancer Hospital Quality Reporting; PRM = patient-reported measure; PRO-PM = patient-reported outcome performance measure; PR-PM = patient-reported performance measure; QCDR = Qualified Clinical Data Registry; VBP = value-based payment.

Our analysis revealed large gaps in the availability of oncology-specific PRMs and PR-PMs related to goal attainment or care concordance, personalized medicine and care planning, socioeconomic status and financial instability, and the population-at-risk phase of cancer care (prediagnosis). Additionally, we identified only 1 caregiver-reported PR-PM, and it did not capture caregiver burden. Likewise, PR-PMs and PRMs that address the follow-up phase of cancer care (post-treatment) generally focused on end of life and did not capture survivorship. Although we found no oncology-specific PR-PMs that assess health behaviors and self-management, this area was better represented with crosscutting PR-PMs.

Landscape findings correspond to the observations of survey participants who identified care coordination (60%) as a high-priority domain of PR-PMs for inclusion in VBP followed by access to care (56%) and symptoms/symptom burden (56%). Supplementary Figure 1 (available in online article) displays the percentage of survey respondents that selected "high priority" for each domain.

PRM AND PR-PM USE IN VBP

CMS has implemented VBP programs that use PRMs to determine provider payment and improve care delivery.[17] Several CMS programs include PR-PMs for an oncology population or clinical process measures that capture PRM use. For example, the Center for Medicare and Medicaid Innovation (CMMI) Oncology Care Model (OCM) includes a patient experience PR-PM and 2 process measures that capture whether providers assessed patient-reported pain or depression using a standard instrument (i.e., a PRM) and completed care planning if the patient screened positive.[18-20]

The oncology-related CMS VBP programs that include PR-PMs or

PRM-related measures are the OCM, the Prospective Payment System–Exempt Cancer Hospital Quality Reporting program (PCHQR), and oncology-specific Qualified Clinical Data Registries for the Merit-Based Incentive Payment System (MIPS; Table 1).

CMMI is testing additional models featuring PRMs or PR-PMs, such as the proposed Radiation Oncology Model and proposed Oncology Care First Model (OCF). [21-23] Other stakeholders have submitted oncology payment models that include PRMs to the Physician-Focused Payment Model Technical Advisory Committee (PTAC), such as the PTAC-recommended Making Accountable Sustainable Oncology Networks alternative payment model.[24,25]

VBP arrangements are also prevalent among private payers, who have begun to implement PRMs and PR-PMs. For example, the Community Health Plan of Washington became 1 of the first private payers to implement PROMs as clinical quality measures in 2018.[26] The interviews and roundtable also discussed how private payers use PR-PMs or PRMs. A health plan representative for 1 organization explained that its contracts require providers to collect and report PRMs but have not yet tied PR-PM performance to payment. Another stakeholder noted that some private payers have included National Committee for Quality Assurance (NCQA) Oncology Medical Home Recognition, which includes several PR-PMs and PRM-related measures, in provider VBP programs.[27] Although NCQA retired this recognition program in October 2019, it encourages practices to instead pursue the Patient-Centered Specialty Practice Recognition program, which requires that practices conduct a patient experience survey (i.e., a PRM) that covers at least 3 of the following concepts: access, communication, care coordination, and person-centered care/self-management support.[28,29]

Collaborations between the public and private sectors have further increased use of PR-PMs in payment and other accountability programs. America's Health Insurance Plans, CMS, and NQF have partnered through the Core Quality Measure Collaborative (CQMC) to promote public and private payer alignment in measures used for quality improvement, transparency, and payment purposes.[30] The CQMC prioritized inclusion of "innovative measures," such as PR-PMs, in its core measure sets.[31]

BARRIERS TO IMPLEMENTING PRMS IN VBP

Though payers have begun to incorporate PRMs and PR-PMs in VBP, the interviews, survey, and roundtable discussion identified several key barriers, discussed in the following sections.

Meaningfulness of Measures. The promise of VBP is that payment will be tied to value. However, the way VBP programs define value, and the PRMs and PR-PMs used to assess it, may not always be meaningful to patients and caregivers. Defining value may be especially complicated for the heterogeneous population of oncology patients challenged with navigating a complex health care system while shouldering physical, social, psychological, and financial burdens. Different patients may have different goals, preferences, and values. For 1 cancer patient, managing pain may be the most important priority, whereas another might value remaining alert. For the latter patient, a PR-PM that assesses level or frequency of pain may be less meaningful than one that captures symptom burden, such as days of work missed. Even when measures address meaningful concepts, they may be specified in a way that is less meaningful. For example, many PRMs capture symptoms, like pain, at a given point in time and miss overall symptom burden.

Methodological Challenges. Roundtable stakeholders agreed that PR-PMs should be held to a higher technical standard when used in accountability programs to ensure that regulatory or financial consequences are tied to accurate assessment of provider performance. Underlying PRMs must fit the purposes they serve, which should drive payer selection of relevant PRMs and PR-PMs. PR-PMs must be valid, reliable, and consider potential sources of bias such as small denominators for some cancer types, sociodemographic or clinical characteristics, and patient desire to "protect" providers.

Patient Burden and Survey Fatigue. Cancer patients interact with the health care system frequently and receive many surveys from various providers. Resulting survey fatigue could be exacerbated by irrelevant and/or complex questions. Additionally, lack of coordination between providers and programs may result in requests for duplicative information. Absence of integrated electronic health record (EHR) systems and flow of information between providers and payers may also contribute to survey duplication.

Provider Burden. Providers may not have resources to implement PRMs in their clinical workflows. Additionally, providers must meet requirements of multiple accountability programs, many of which do not provide sufficient incentives to offset investment needed to implement PRMs and report PR-PMs.

Recommendations for Accelerating Progress

Our multimethod analysis yielded actionable recommendations for public and private payers to increase appropriate use of PRMs and PR-PMs in oncology VBP programs. Because much activity is underway, these recommendations

focus on accelerating progress through measure development, program design, and implementation.

SUPPORT DEVELOPMENT OF MEANINGFUL MEASURES

Some public and private payers develop measures or fund measure development. To capture elements of care process and experience that are most meaningful to cancer patients, payers should engage patients and caregivers in development and ongoing evaluation of PRMs and PR-PMs.

Development work should aim to fill current gaps in availability of oncology PRMs and PR-PMs: goal attainment or care concordance, personalized medicine and care planning, socioeconomic status and financial instability, population at risk, caregiver burden, and survivorship. Payers could leverage existing crosscutting PRMs to develop oncology-specific PR-PMs to fill some of these gaps. Public payers can also fill current gaps by offering measure development grants and continuing to fund relevant initiatives. For example, the CMS Meaningful Measures initiative and the Department of Health and Human Services Quality Summit demonstrate a move toward outcome measures that are meaningful to patients.[32,33]

Payers developing or modifying PRMs should eliminate questions that are less useful or meaningful to increase patient response rate and generate more accurate data. If PRMs are available in a platform that allows patients to skip irrelevant questions, while maintaining validity and reliability, overwhelmed cancer patients will have less burden from completing extensive surveys.

Private payers can collaborate with measure developers and professional societies to generate new measures and may have capacity to create and implement custom measures to apply to their networks. For example:

- Optum, a part of UnitedHealth Group, is listed as steward for 10 quality measures in the NQF QPS (identified using the "measure steward" filter).[34]
- ActiveHealth Management, a population health management company and subsidiary of Aetna, stewards 28 measures in the QPS.[34,35]
- HealthPartners, an integrated health care organization with a health plan, has developed measures for over a decade.[36,37]

Private payers should also participate in national efforts to create appropriate PRMs and PR-PMs. For example, the CQMC has identified "patient experience/PRO for level of pain experienced by patient" as a future development opportunity in its Medical Oncology Consensus Core Set to be implemented across commercial and government payers.[38,39] Payers could also explore opportunities to participate in collaborative projects related to patient-centered

measurement funded by organizations like the Patient-Centered Outcomes Research Institute.[40]

SELECT MEANINGFUL, SCIENTIFICALLY SOUND, AND STANDARDIZED MEASURES FOR PROGRAMS

Public and private payers should involve patients and caregivers in the design of VBP programs and include patient involvement in development as 1 criterion for selecting PR-PMs for program use. Payers can also promote use of meaningful measures by selecting PR-PMs that address areas identified as priorities on the survey and in the roundtable, such as care coordination, access to care, and symptoms/symptom burden, for new programs or future versions of programs such as OCM/OCF. Measures of symptom management, specifically, can help payers identify at-risk patients, improve population health management, and decrease utilization of health care services.

Payers should select valid, reliable, and fit-for-purpose PRMs and PR-PMs for value-based programs to ensure that providers are fairly assessed on measures that affect their payment. Using PR-PMs that have been endorsed by NQF is one way to ensure validity and reliability.[41] Additionally, many published PRMs include measure testing results, describe the population on which the PRM was tested, and discuss the psychometric properties. This may help a payer determine if the measure is valid, reliable, and has been used in a similar setting.

To address bias related to small denominators in rarer cancer types, program designers should include crosscutting PR-PMs, address measures at the group or system level, and consider combining multiple years of data. Crosscutting measures may also better encompass diverse cancer types and treatments in broader VBP programs.

Payers should work to align PRMs and PR-PMs across programs and select standard PR-PMs and/or PR-PMs built from standard PRMs to reduce provider and patient burden. Selecting crosscutting PR-PMs derived from PRMs that also have condition-specific questions may decrease burden and improve care by enabling providers to use the same instrument for clinical care, quality improvement, and accountability purposes.

INCENTIVIZE IMPLEMENTATION

Payers and program administrators should use a stepwise approach to engage providers in implementation:

1. Offer incentives and provide resources, like technology, to assist providers in initial implementation of new programs.
2. Set realistic expectations for implementation and performance, establishing thresholds for providers to use as benchmarks.

3. Allocate implementation time for providers and programs to gather and analyze data.
4. Use a learning feedback loop to calibrate approaches to improve program structure, PRMs, and PR-PMs.
5. Give providers time and information to improve both PRM administration and PR-PM performance.
6. Institute VBP and begin evaluating additional PR-PMs.

The first of these steps is critical. Implementing PRMs can require substantial resources, and without strong incentives, providers may not be willing to undergo the effort. Public and private payers can drive change by offering training, grants, resources, and additional incentives to fund implementation and administration of PRMs and PR-PMs in VBP programs. For example, payers could offer a per member per month (PMPM) payment for providers to implement PRMs as a component of oncology infrastructure improvements. PMPM payments would incentivize implementation and enable providers to use PRMs to better manage oncology patients and populations. This could reduce public and private payer costs via patient-centered efforts to better control symptoms, reduce unplanned utilization, and improve patient experience of care.

Payers should offer technology, or funding for technology, to capture symptoms and symptom burden, beginning with initiation of cancer treatment. For example, CMS could offer subsidies for EHR vendors to incorporate standardized PRMs into their systems. Private payers might supply PRM software to network providers at no charge. Technology can help providers assess and respond to symptoms throughout treatment, allowing payers to avoid downstream costs, such as unnecessary ER visits. The National Health Service of the United Kingdom has advanced PRM technology by publishing a Cancer-Related Fatigue application that helps patients manage symptoms, reducing fatigue and increasing happiness.[42] In France, a randomized trial found an association between monitoring lung cancer symptoms via web-based PROs and increased survival.[43] Web-based surveillance is also cost-effective compared to conventional surveillance.[44]

Conclusions

Cancer patients face many challenges, including navigating a complex health care system while experiencing high symptom, psychological, and financial burdens. Their perspectives are paramount to understanding quality and value of care they receive. Using PRMs and PR-PMs not only captures the value of cancer care from patients' perspectives but can also hold providers accountable for patient needs, improve patient experience and outcomes, and reduce costs for payers.

Payers play a critical role in defining value, shaping provider behavior, and influencing patient outcomes in oncology. By supporting meaningful PRM and PR-PM development, designing programs with appropriate PRMs and PR-PMs, and incentivizing implementation, payers can help ensure that VBP programs promote delivery of patient-centered, high-value care for cancer patients and their families. Payers should commit to continuously improving oncology-related PRMs, PR-PMs, and value-based programs that use them.

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