

[PQA Session: Filling Gaps in Patient-Reported Performance Measures for Oncology](#)

At the [Pharmacy Quality Alliance Annual Meeting](#) on May 16, 2019, Ms. Theresa Schmidt moderated the panel, *Filling Gaps in Patient-Reported Performance Measures for Oncology*, with panelists [Dr. Karen Fields](#) of the Moffit Cancer Center and Napkin Notes Dad [W. Garth Callaghan](#).

The panelists noted that patient-reported measures (PRMs) can help bring patient voices into accountability programs, but difficulty developing methodologically sound PRMs and implementing meaningful patient-reported performance measures (PR-PMs) has contributed to gaps in the availability of PR-PMs for programs that hold providers accountable for performance (accountability programs). This is especially challenging in oncology where the treatment, the daily lived experience, and outcomes for different patients vary widely.

According to Ms. Schmidt, “While our research uncovered over 800 PR-PMs in the overall landscape, we only found 18 specific to oncology, and there are major gaps related to goal attainment and care concordance, socioeconomic status and financial toxicity, personalized medicine and care planning, caregiver burden, and survivorship.”

“The promise of including the patient voice in programs is to ensure that the things that are meaningful to patients are incentivized,” noted Dr. Fields. “Implementing appropriate PR-PMs in accountability programs will encourage providers to focus on key processes and outcomes that can be measured in a variety of oncology settings.”

However, even existing PRMs and PR-PMs may not be meaningful to patients. As a patient who has been diagnosed numerous times with metastatic kidney and prostate cancer, Mr. Callaghan reported receiving many surveys (i.e., PRMs) as a part of his treatment that he does not find meaningful and noted, “I’m not confident that the data are always used, but I’m always willing to answer questions when I believe the information could be used to help other patients.”

One of the key recommendations of the panelists was to involve patients and caregivers in the design and development of both measures and of value-based payment programs to ensure that measures and programs are meaningful and truly assess “value” for patients. The panel discussed three critical elements for engaging patients in these processes:

- Communicate the purpose and value of a given measure and “what’s in it” for the patient
- Demonstrate how the data will be used to improve patient care
- Show how participation contributes to a greater cause (i.e., the betterment of the patient and caregiver community)

Ms. Schmidt closed the panel by summarizing, “Patients and caregivers must have a voice in the development and implementation of PRMs and PR-PMs, but voice without action is meaningless.” Gap-filling activities should include efforts to involve patients in measurement processes, align incentives to what is meaningful to patients, and increase transparency.

ISPOR Session: Controversies Around the Use of Patient-Reported Measures in Oncology

Ms. Schmidt also moderated a panel at the [ISPOR 2019](#) annual conference in New Orleans on May 21, 2019 with panelists Napkin Notes Dad [W. Garth Callaghan](#), [Dr. Yousuf Zafar](#) from the Duke Cancer Institute, and [Dr. Cynthia Grossman](#) from Biogen. The panelists brought together the patient, provider, and research perspectives to provide insight on the benefits, risks, and barriers to implementing patient-reported performance measures (PR-PMs) in value-based payment (VBP) programs for oncology. This session was highlighted as one of the [Evidence Base “Editor’s Picks”](#) from the ISPOR agenda.

Ms. Schmidt began the discussion by asking whether provider payment should be impacted by patient-reported measures (PRMs) and PR-PMs. “As a patient,” Mr. Callaghan said, “this makes me very nervous. I would not want my doctor to make decisions about my care based on the expectation that my answers to a survey will impact their payment.” However, Dr. Zafar observed, “Providers are already making decisions based on payment, so including appropriate PR-PMs may help them focus on care that is more important to patients.”

Public reporting of PR-PMs was generally viewed favorably. According to Dr. Grossman, “Public reporting of PR-PMs may be more systematic and unbiased than social media,” but Mr. Callaghan noted, “If patients and families cannot understand the measures or process for collecting data, the information is not helpful.”

Mr. Callaghan described the lack of understanding most patients have about what happens to PRM data: “Why should patients take the time to complete surveys without visibility into the way they are used?” However, Dr. Zafar noted, “Current PR-PMs are a starting place and capture some key care processes and outcomes from the patient perspective. Collecting PRMs may improve monitoring of key patient outcomes and individualizing treatment.”

Dr. Grossman and Dr. Zafar agreed that measures should be quantifiable, truly reflect the care being provided, and address quality of care. Conversely, measures that may be unreliable, do not adjust for risk factors, or do not reflect actual provider performance should be avoided.

Panelists made recommendations for increasing the benefits to patients and decreasing the burden of measurement:

- Use longitudinal patient-level data in clinical care
- Describe the importance of PRMs and how the data will be used
- Administer PRMs during appointment wait times (e.g., during chemo)
- Administer electronic rather than paper-based surveys
- Use standardized instruments that are individualized to ask only relevant questions
- Adopt computer adaptive testing tailored based on patient responses

“If we accept that policymakers will continue to include PR-PMs in VBP programs, and we believe that current measures may not be sufficient to capture concepts that truly measure value for patients, who should fund efforts to create PR-PMs, standardize or enhance PRMs, and support implementation of measures and programs?” asked Ms. Schmidt.

Panelists cited public and private payers as important funding sources, but Mr. Callaghan closed this discussion by observing, “Ultimately, I suspect that patients will end up being the ones who pay for

these initiatives.” This statement reinforces the need to ensure that the use of PR-PMs in VBP programs improves care and increases true value for patients.