

PIPC's 9th Annual Forum: Building Patient-Centered Value Standards

12/16/2018



As health care policymakers are proposing new payment incentives and building so-called “value standards,” patient advocates and health policy experts have concluded that patients and people with disabilities should lead the way on creating new solutions. That was the message from a panel of leading experts on defining “value to the patient,” who joined a spirited discussion on the future of value-based care at PIPC’s 9th Annual Forum in Washington D.C.

Speakers on the Forum’s distinguished panels included:

- **Jennifer Bright**, Innovation and Value Initiative;
- **Dr. Joey Mattingly**, University of Maryland Baltimore School of Pharmacy, PAVE Center;
- **Josh Seidman**, Avalere;
- **Kristin Carman**, Patient-Centered Outcomes Research Institute (PCORI);
- **Ari Ne’eman**, PIPC and Disability Advocate;
- **Eric Gascho**, National Health Council; and
- **Rebecca Kirch**, National Patient Advocate Foundation.

While the panelists concluded that the move to “value” can help patients by promoting access to affordable care that they value, in practice, it became apparent that many real-world examples of moving to value leave patients and people with disabilities behind. Instead, the panelists outlined a slate of alternative, evidence-based strategies that represent the future of how the health care system can make decisions that reflect the values of patients.

The ADA: A ‘First Step’

PIPC Chairman Tony Coelho opened the discussion with a timely reminder of how far the disability community has come in eschewing discrimination and exclusion to gain a legitimate seat at the table in the public policy arena. In remembering the passing of President George

H.W. Bush, Chairman Coelho recalled that “Before 1990, people with disabilities couldn’t get jobs, often couldn’t access public spaces or restaurants and were too often hidden from society.” When President Bush signed the Americans with Disabilities Act (ADA), “it was just the first step,” he added.

Since passing the ADA, Chairman Coelho outlined how the policy debate has continued to evolve. In 1992, he detailed how HHS told states that using discriminatory value assessments relying on what is called the “quality-adjusted-life-year” (QALY) to determine what they cover in Medicaid was a violation of the ADA. Later, he added, Congress put that in statute by banning the use of QALYs in Medicare. But today, he expressed concern that health economists in academia still use QALYs to determine cost effectiveness of treatments, and private insurers then use those cost effectiveness reports to determine whether to cover treatments.

In welcoming the first panel, Chairman Coelho emphasized that these innovative thinkers have the potential to become “the next generation of leaders” that support a patient-centered healthcare system that does not discriminate against people with disabilities or serious conditions. “Because no patient is average,” he said. “And no patient should be denied access to care just because they have significant health needs or don’t fit into an average cost effectiveness framework.”

Building Alternative Value Standards



PIPC’s Executive Director Sara van Geertruyden, who moderated the panel discussions, provided an overview of PIPC’s work to promote value-based strategies that improve access to care. Unfortunately, as Mrs. van Geertruyden explained, payers are increasingly relying on traditional cost effectiveness studies that marginalize patients and people with disabilities. “We see aggressive utilization management tools such as step therapy based on non-transparent judgments about comparative effectiveness and value,” she explained. And these value judgements “too often rely on a discriminatory assessment of the cost-per-QALY.”

Mrs. van Geertruyden went on to introduce the panelists, who she explained present a unique perspective on new solutions that are “outside the box of traditional research and value assessment.” Among the highlights of the panel discussion:

- **Jennifer Bright**, Executive Director for the Innovation and Value Initiative (IVI), emphasized how value assessment should overcome “one size doesn’t fit all.” While she

explained that some value assessments use the term ‘patient-centeredness’ in a way that is not “authentic,” she said that the IVI strives for genuine patient engagement by meeting with patients to determine how they define ‘value’ in a particular disease state. “We want to take that research a step further to quantify those perspectives on a level playing field with clinical and cost effectiveness research data,” she said. Ms. Bright went on to explain how the IVI model is “open source,” which allows for public input from developers, users, and patients. By creating an open source value assessment framework, she expressed hope that the IVI will “create trust” among patients that their voices are being heard and their input is valued.

- **Dr. Joey Mattingly**, a researcher at the University of Maryland Baltimore School of Pharmacy’s Patient-Driven Values in Healthcare Evaluation (PAVE) Center, has dedicated his research to pharmacoeconomics and patient-engagement. Despite his expertise, though, Dr. Mattingly acknowledged that “no matter how hard I study... I can’t understand what it’s like to be a patient with a certain disease.” That’s why, he said, patient engagement is paramount at the PAVE Center, and each meeting that they hold starts with a story from a patient. By having patient representatives chair important committees and making a conscious effort to reduce bias, Dr. Mattingly said that the PAVE Center seeks to empower patient stakeholders to analyze existing value assessments and educate them on how to respond.
- **Josh Seidman**, a Senior Vice President at Avalere, discussed the Patient-Perspective Value Framework (PPVF). As he explained, the PPVF is a new way to assess the value of healthcare services that considers factors that matter to patients — such as functional and cognitive status, symptom relief and side effects, complexity of regimen, and financial incentives to the patient and family — and weights them in accordance with assessed patient preferences. Mr. Seidman explained that “we aren’t saying that costs shouldn’t be considered, but we’re starting with the perspective of the patient.” He also detailed how financial costs don’t just reflect out-of-pocket medical costs, but must also account for factors including travel, time off from work, productivity, caregiver engagement, and administrative burden. Further, Mr. Seidman explained that “no patient is average... the effects of treatments are variable.” He concluded that they are currently developing an upstream shared decision-making tool — a so-called “care journey roadmap” — which they soon plan to pilot.
- **Kristin Carman, MA, PhD**, the Director of Public and Patient Engagement at PCORI, suggested that PCORI is “uniquely situated” to feed into the sort of patient-centered value frameworks highlighted by the other panelists. As she explained, the mission of PCORI is to generate evidence and information to support patient-centered decision-making. Dr. Carman highlighted PCORI’s process for stakeholder input, which in concert with their statutory mission is essential in ensuring the patient is at the center of the Institute’s research initiatives. “Our studies and the outcomes we measure are especially patient-centered — we focus on what matters to patients,” she said. Further, Dr. Carman said that PCORI has been particularly focused on measuring patient-reported outcomes, which she said are essential in telling the patient value story — including quality of life, burden, and other issues.

Patient and Disability Perspectives



Following the panel on alternative value standards, Ms. van Geertruyden introduced a second panel featuring a trio of leading patient and disability advocates to share their perspectives on the importance of patient-centered value assessments. Among the highlights of the second panel discussion:

- **Ari Ne’eman**, a disability advocate and co-founder of the Autistic Self Advocacy Network, provided a detailed accounting of concerns with value-assessments that rely on QALY calculations. As he explained, “the essence of the QALY is a desire to measure through a single number both morbidity and mortality... to compare the cost-effectiveness of drugs and interventions across different diagnostic categories.” These assessments often rely on calculations of “disability weights,” he said, which are used to determine how much less the life of a person with a disability is worth compared to someone without that disability. Importantly, he explained that this has significant implications on what patients get access to. “If you are part of the large segment that is not going to be cured, but is going to live with a disability, the cost-effectiveness framework that measures the value of extending your life carries less weight than extending the life of a non-disabled person,” he said. Looking forward, Mr. Ne’eman cited several specific examples of instances where advocates must push back against the use of the QALYs in public and private programs: use of the Institute for Clinical and Economic Review (ICER) reports; attempts to lift PCORI’s ban on using QALYs; CVS’ partnership with ICER; and New York State’s Medicaid program.
- **Eric Gascho**, the Vice President of Policy and Government Affairs at the National Health Council, spoke to how their organization is working with individual patient groups to engage in value assessment. He lamented ICER’s history on patient engagement, noting that many organizations have not been aware that ICER has been planning to examine their conditions. To facilitate such engagement, he explained that NHC has created best practices for engaging with groups like ICER and other value assessment organizations. Mr. Gascho said that while there have been improvements on bringing in patient perspectives to value assessments, there are also limitations to the data that can be used — they are typically looking only at clinical trial data. Also, he pointed out that the QALY has likely been relied on so heavily only because there are currently few alternatives for value assessment frameworks. “QALYs had a 10-year head start,” he said, “but we need to do better at creating methodologies that incorporate the patient definition of value.”

- **Rebecca Kirch**, the Executive Vice President of Health Care Quality and Value at the National Patient Advocate Foundation (NPAF), spoke about her personal experience in managing her husband's health issues. As payers minimize the importance of function and quality of life as not being "medically necessary," Ms. Kirch pointed out that provider accreditation standards can be used to drive high standards of care. For example, she cited opportunities for the Joint Commission to develop patient-centered quality standards for practitioners to use. Moreover, she encouraged PCORI to examine the impact of clinical teams being equipped to elicit info from patients and caregivers their preferences. Patients that are activated in their care and treatment decisions are more likely to achieve favorable health outcomes, and Ms. Kirch emphasized how the patient experience could be improved while still remaining conscious of costs. She compared rigid formulas for assessing value to the formula described in the TV show, "The Good Place" as an example of their misguided results for real people.