Using PCORI to advance patient-centered values

by R. Brett McQueen, Joey Mattingly
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As the debate over costs, value and insurance coverage in the U.S. continues to ramp up, it will be increasingly important to ensure the patient perspective is the centerpiece of these discussions.

Value assessment has become a critical part of these discussions as stakeholders look for better ways to measure the value of healthcare interventions, including drugs, devices and procedures.

Patients have historically been—and often continue to be—excluded from decisions that shape the value assessment dialogue.

The Patient-Centered Outcomes Research Institute (PCORI) was authorized by Congress in 2010 to facilitate ways to improve healthcare delivery and outcomes using an explicitly patient-centered approach. The organization’s research mandate is to conduct high-quality comparative-effectiveness research (CER) and support patient-centered outcomes research (PCOR) to inform patient decision-making in today’s complex and multifaceted healthcare system.

PCORI is unique among major U.S. research funding organizations in bringing the patient perspective to CER. But it has not yet clearly achieved the goal envisioned by policymakers of “connecting the dots” back to value.

In fact, while it has made great strides in establishing the field of CER-PCOR, PCORI is prohibited from conducting cost-effectiveness analyses for treatments to determine their value. In other words, PCORI-supported researchers study how various medical treatments compare in improving health outcomes but do not get involved in comparing costs per health outcomes achieved.

Nonetheless, the platform PCORI has created is ideally suited to capturing the elements of value that matter to patients. In fact, a recent examination of one of the largest databases of comparative effectiveness and cost-effectiveness studies to see how often there is disagreement between the two types of analyses found that both agree on the best treatment
about 80% of the time. This shows that PCORI is a valuable resource underutilized by a health ecosystem that is trying to target value.

It’s time to recognize this resource to properly build upon and leverage its potential. That’s not to suggest that PCORI take on the role of value assessor or begin conducting cost-effectiveness analyses. Instead, PCORI should build upon and enhance its CER-PCOR platform to further the production of the patient-centered, comparative effectiveness data needed for others to conduct sound, patient-centered value assessment. Stated differently, the fundamental challenges in value assessment are how to measure and compare clinical and health benefits, and PCORI is well-positioned to help meet these challenges.

To illustrate how PCOR could be used by researchers to better inform the value dialogue, look no further than the PAVE (Patient Driven Values in Healthcare Evaluation) Center at the University of Maryland School of Pharmacy. Formed in partnership with the National Health Council, PAVE aims to leverage PCOR to inform value assessment approaches through direct engagement with individuals from diverse patient communities.

PAVE is helping the field of value assessment better understand that treatments are valued differently by different patient populations and is working to develop novel patient-centered value elements—such as the impact of an illness on families or caregivers, differences between individuals or subpopulations, time horizons, input parameters and more to help drive care decisions. Researchers are also seeking to understand how to improve the so-called “Reference Case,” used to facilitate comparability among cost-effectiveness analyses, can be improved to feature greater inclusion of the patient perspective.

These insights are needed so that employer and payer coverage decisions can be tailored to unique patient populations. This year PAVE has been conducting research on chronic obstructive pulmonary disease, hepatitis C and pediatric food allergy to identify the value elements of interest in these unique patient populations.

This approach has been especially crucial in helping understand the preferences of patients not traditionally engaged in research.

Currently, researchers are working with the Latino community in the Baltimore-Washington metropolitan area to identify patient-driven value components and create training modules to ensure the values of people of diverse ethnic and cultural backgrounds are accurately reflected.

Moreover, other research centers around the country would benefit from PCORI’s patient-centered research results.

Pharmaceutical Value (pValue) was formed at the University of Colorado School of Pharmacy with a mission of applying and testing novel healthcare value assessment methods to guide coverage and reimbursement decision-making. Specifically, pValue plans to complement traditional value assessment approaches by quantifying nontraditional aspects of value (e.g., equity) from multiple stakeholders, including patients, using multicriteria decision analysis.
MCDA can be helpful for coverage and reimbursement decision-making where standard-of-care therapies and their alternatives are characterized by multiple, often conflicting criteria.

In addition to traditional value assessment approaches, planned experiments led by the University of Colorado pValue initiative will help determine where expanded decision tools should be used alongside traditional approaches.

We need to make it a national priority to do a better job capturing value from the perspective of patients.

Health outcomes should primarily flow from patients. Costs are not that simple and involve multiple stakeholders within the world of insurance. Therefore, when rolling up the subdomains into value, identifying the importance of criteria within the subdomain of outcomes becomes an important scientific endeavor.

The patient voice is pivotal and PCORI 2.0 is well-suited to fund such endeavors.

Congress must reauthorize PCORI so that it can build upon its foundational work and go the next step to generate CER-PCOR on outcomes that can inform and strengthen patient-centered value assessment. PCORI has outlined the path. Groups like PAVE and pValue are stepping up to put data into action.

Joey Mattingly, Ph.D., is an associate professor at the University of Maryland School of Pharmacy where he serves as director of operations for the PATIENTS Program.

R. Brett McQueen, Ph.D., is an assistant professor at the University of Colorado School of Pharmacy where he is a core faculty member in the Center for Pharmaceutical Outcomes Research and co-investigator with pValue.