



Making the Patient Voice Matter In Value Assessment

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Conversations about the value of health care treatments have not traditionally included the patient perspective. In the past, value has been measured through cost-effectiveness analyses that weigh the clinical benefits of a treatment against its costs without a consideration of how those benefits align with what patients want from a treatment. Value-assessment efforts often included highly qualified health care providers and health economists. But there has been no seat at the table for individuals who live day to day with the condition being assessed. We have begun to recognize the importance of having patients more consistently engaged both in the generation of evidence and in the determination of what is of value to patients in health care decision making. Including the patient voice in value assessment can ensure that health care decisions do not overlook the aspects of treatment that are truly important to patients.

But how do we determine what those aspects are? Even more crucially, how do we ensure they are meaningfully incorporated into these assessments in a way that captures the true value of these treatments?

Until these questions are answered thoroughly, treatment value assessments will continue to lack a process for incorporating what patients truly value in their care.

Researchers at the Patient-Driven Values in Healthcare Evaluation (PAVE) Center at the University of Maryland School of Pharmacy are taking a multistakeholder approach to addressing these questions. Our team is investigating approaches for incorporating patient perspectives into value assessments through direct engagement with individuals from patient communities. This includes groups, such as minorities and people who are under- or uninsured, that have traditionally been underrepresented in the value-assessment space. The work focuses on ensuring that the patient voice remains a crucial part of treatment evaluations. We work with patients not as research participants in a study, but as stakeholders and content experts with as much to offer as the clinicians and economists on the research team.

Our work has led us to develop a novel set of patient-driven value elements, including the impact of a treatment on the family, and the impact of treatment on physical abilities, the ability to maintain social relationships and take part in social activities, and the ability to plan for the future.

They can—and should—be included in the value assessment of treatments.

The next step is to apply these patient-driven value elements in practice working with specific patient communities. We have identified chronic obstructive pulmonary disease as an initial therapeutic area to test these value elements and are working on a framework that would fold them into economic evaluations of treatments and interventions for the disease. Over the next several months, our team will test different methodological approaches for treatment value assessment. We will be engaging patient stakeholders every step of the way.

In parallel to developing a patient-driven value assessment framework, PAVE also includes an educational component to expand patient capacity to engage in value assessment and to ensure that individuals conducting value assessment are appropriately trained in how to engage with diverse patient populations, especially minority and underserved patient populations. The investigators within PAVE and collaborators at the National Health Council have longstanding relationships with many patient communities that make this kind of outreach possible. Our team is committed to building on relationships we've established over the better part of a decade, engaging with patient groups in other disease areas that have been instrumental in establishing partnerships with Latinx communities.

It is our hope that by truly listening to and incorporating the patient voice in value assessment, we can gain a better understanding of how treatments are valued differently by different groups. We can then use that knowledge to ensure patients are receiving treatments that are right for them.

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