



# ALERT

*Supporting research and early career endeavors of scientists in drug discovery and development*

---

## **Racial and Ethnic Disparities in Health Care are Found in the Missing Patient Voice**

*(The PhRMA Foundation continues to post new content to its Value Assessment blog, "Voices in Value." **Wendy Camelo Castillo, MD, MSc, PhD**, of the University of Maryland, recently contributed the essay below, addressing racial and ethnic disparities in health care. She is lead coordinator of Patient-Driven Partnerships in the Hispanic Community within the Patient-Driven Values in Health Care (PAVE) Center of Excellence.)*

COVID-19 has exposed dramatic vulnerabilities in our society and it is becoming clearer that minority communities are hit harder than most. The virus has also shined a spotlight on the racial and ethnic disparities in our health care system with a disproportionate number of people of color caught up in its path. What has led to this moment is decades of disenfranchisement within a health care system that has unquestionably failed to provide appropriate avenues for these communities.

In order to fully benefit from the medical options available today, minority communities must be seen and heard, feel confident in voicing their needs, concerns, and preferences, and be able to define for their clinicians what the value of a specific treatment or care plan is to them — what matters and what matters most when it comes to their health.

Fortunately, there is a research effort in progress that is working to find and amplify that voice.

The Patient-Driven Values in Healthcare Evaluation (PAVE), a Center of Excellence in Patient-Driven Value Assessment was formed with the specific goals of using a stakeholder-engaged and an empirically driven process to identify patient-informed value elements, determine how those elements can be incorporated into existing value frameworks, and test the value elements in economic evaluations. But what does that mean to patients — particularly those who struggle with language barriers, limited resources and knowledge about how to access health care or to communicate effectively with their providers what is most important to them regarding treatment and outcomes?

Five years ago, we put together an initial strategy to identify the communities who have historically been invisible in value assessment research. To understand the missing voice in patient diversity, PAVE began exploring what value means for individuals whose voices are under-represented in value assessment. In particular, we are assessing how racial/ethnic minorities, uninsured and underinsured patients' value health and whether their perspectives differ to those more often reflected in patient communities with greater resources.

Our vision comes to light in three dimensions — because the patient voice is diverse and dynamic:

1. **The lived experience.** This represents the experience of those living with a health condition and the decisions that they face to regain or maintain health.
2. **The patient organization.** This represents established patient organizations, which typically advocate to affect change for the overall/average patient experience or to influence policy.
3. **Patient community diversity.** Within patient communities what is valued in health is influenced by the context and background of the majority. The diversity within patient communities and how this may affect treatment preferences and decision-making has seldom been discussed. *This is the missing voice.*

To begin our journey into what is largely uncharted territory, we initially focused on the Hispanic community in the Baltimore-Washington Metropolitan area. This is one of the largest and fastest growing minorities in the State of Maryland with diverse representation of first- and second-generation immigrants, Spanish-only and bilingual individuals from various countries of origin, and representation from within a range of socio-economic levels. The diversity of this community has proven to be ideal for exploring issues of race, socioeconomic factors, and access to healthcare insurance as this relates to what is valued in health.

Our goal was to build relationships and connections both at the community level and the larger patient advocate organizational level. Looking to community leaders that were not necessarily a part of a structured organization but rather had their ear to the ground, was our best option.

We were fortunate to come upon and form a partnership with Juan Caicedo, the Executive Director of Heritage Care, Inc. Juan has a keen understanding of the different needs in the area Hispanic communities, particularly of health care and education. Under his tenure, Heritage created a free clinic for uninsured, economically challenged communities and free English as a Second Language (ESL) classes for these communities. They continue to provide services to the Hispanic community, most recently providing pediatric therapy services to children with disabilities, as well as adult education ESL and health care classes.

Juan is one of our valued stakeholder advisors on the PAVE steering committee. His extensive knowledge and years of experience advocating for the community helped us understand the many layers to consider when attempting to elicit the missing voice in value among the Hispanic community. We found that some families have limited or no access to health care and are more vulnerable to develop chronic conditions and to experience preventable hospitalizations or poor outcomes.

The language barrier for many in the Hispanic community can have detrimental rippling effects. These individuals may not fully understand the health care options being offered to them. For those with health insurance, navigating what treatments or procedures are covered and what costs they can be billed for beyond their co-pay can be confusing, as well as take a toll on families in financial distress.

PAVE's next steps to incorporating the patient voice in value assessments includes assessing how diversity affects the value placed on treatment decisions as well as the tradeoffs patients are willing to make. Strategies to engage underrepresented communities and grassroots organizations by working side by side with those at the community level who are directly in touch with individuals, will lead us to developing research approaches that capture this diversity to inform value assessments.

In the era of value-based care and personalized approaches, PAVE is moving the field forward by developing strategies that will enable diverse and under-represented communities engage meaningfully in conversations about value in health care, and what it means for their lives and their communities. We are hoping the outcome of our research can contribute to closing the gap ethnic groups experience in health care and ultimately helps shape a health care system that benefits all of us.

*(Wendy Camelo Castillo, MD, MSc, PhD is an Assistant Professor in the Department of Pharmaceutical Health Services Research, University of Maryland School of Pharmacy*

based in Baltimore, Maryland and lead coordinator of Patient-Driven Partnerships in the Hispanic Community within the Patient-Driven Values in Health Care (PAVE) Center of Excellence. PAVE is a PhRMA Foundation Center of Excellence.

*This post was first published on PAVE's [blog](#), which is hosted on Medium. It is republished here with permission from the author.)*

###

### **About the PhRMA Foundation**

The mission of the PhRMA Foundation is to improve public health by proactively investing in innovative research, education and value-driven health care. For 55 years, the Foundation has been helping advance scientific research and innovation to benefit patients. Since its founding in 1965, it has distributed more than \$99 million to support these efforts. The PhRMA Foundation accomplishes its mission by investing in three key areas: core programming, value assessment initiative and a new program under development in the use and application of Data and Technology in Health Care. The PhRMA Foundation's core programs of Drug Delivery, Drug Discovery, Health Outcomes Research and Translational Medicine encourage young scientists to pursue research as their career choice and assists in training the next generation of innovators. The PhRMA Foundation's emphasis on evidence-based research that determines the true value of medicines is supported by its [Value Assessment Initiative](#). To learn more, please visit [www.phrmafoundation.org](http://www.phrmafoundation.org).

---

[Visit our website for more information](#)

PhRMA Foundation | Phone: 202-572-7756 | Email: [foundation@phrma.org](mailto:foundation@phrma.org)

STAY CONNECTED

