



WCG

WCG Patient Forum -

# Increasing Diversity & Equity in Medical Care & Clinical Trials: Strategies to Build Trust, Engage Patients & Break Through Barriers



## BUILDING TRUST

For any relationship to flourish, there must be trust. "In the African American community, there has been a history of mistrust and distrust because of things that have happened with Henrietta Lacks, the Tuskegee airmen and some other experiments," said Beverly Francis-Gibson, president and CEO of the Sickle Cell Disease Association of America. The pharmaceutical industry needs to understand patient hesitancy and bring that sensitivity to the conversation so we can move forward. To recruit diverse patients for clinical trials, the participants must feel they can trust the pharmaceutical or biopharmaceutical companies involved. Along with clinical trial information, we can provide information about the sponsors: What are their philosophies? What is their mission?

We need more options for patients who are needlessly suffering and dying. In the case of sickle cell disease, for example, there are only four FDA-approved drugs on the market. The way to initiate more studies for this disease is to leverage relationships with minority communities nationwide, plus patient advocacy groups, to encourage more patients to begin and complete trials. These participants need to feel that the sponsors and clinical trial sites involved – which may include large hospitals, institutions, community clinics or small clinics – are conducting these trials with their best interests in mind.



and going to medical school, along with the importance of mentoring. Finally, we heard from a scientist leading clinical research at a major healthcare institution in the Rio Grande Valley, who has come home to where she grew up as a Mexican American in a predominantly Mexican American community. She helped us understand how the most modern science and clinical research methods combine with culturally competent communication approaches to win trust and participation from underserved ethnic communities.

"This entire event is a call to action for clinical trial professionals faced with questions of how to overcome the access barriers that prevent participation in clinical research by underserved minorities," noted Steve Smith, president of Patient Advocacy for WCG. "The real solutions presented, articulated by members of the communities in question who make these solutions work, are inspiring and informative."

How do we envision developing a more clinical-trial-savvy population? Many people lack information about clinical trials and what they entail in terms of family impact or quality of life. If they have the opportunity and encouragement, patients will participate to benefit their own health – or humanity in general. We hear patients say, "I may not benefit from a clinical trial in my lifetime, but I want to know that I am contributing to sickle cell disease treatment for future generations." They are willing to sacrifice for the betterment of their community, so we need to build trust and encourage this support.

## **ENGAGING MINORITY PATIENTS**

When we are transparent and demonstrate the benefits of clinical trial participation, we will see a response from the community. Then, we can ask participants to share their stories with others, and they will help us bring more people into the fold. If we do our job well, we can start a new trend and engender more support, participation and knowledge surrounding clinical trials. In the long term, we will dispel some myths, as well. In contrast, if patients feel exploited or abused, they will share those perceptions with their communities.

We need liaisons between the pharmaceutical industry and the patient community.

"Companies don't fully understand what life is like for someone living with sickle cell disease," noted Francis-Gibson. "Sponsors may create

a trial expecting sickle cell patients to travel to another state and reside in a hospital for two to three months. However, many of these patients practically live in hospitals already, or they may have jobs and not be able to take time off from work. Also, patients may have families with small children. Especially during COVID, sickle cell patients are avoiding travel of any type." A liaison can provide education on the patient perspective so that sponsors can design trials for success.

Another approach for engaging minority patients is via trained community health workers. For example, the Sickle Cell Disease Association of America (SCDAA) has a certified curriculum to train lay individuals to become community health workers. They place these workers in local communities with SCDAA member organizations and at clinics and hospitals. Why is this helpful? These trained workers know the community, and they are trusted. Sponsors can provide extra expertise as needed to help direct them, guide them and respond to patient inquiries. This community health worker model is one that we can expand for other diseases. It can help amplify healthcare messages as workers speak directly with patients, understanding what they are experiencing.

## **BREAKING THROUGH BARRIERS**

We know that minorities are underrepresented in clinical trials. We understand that we



must ensure that clinical trials represent the populations that can benefit from medical breakthroughs. The effort begins with identifying the barriers to healthcare and clinical trial participation. These barriers are primarily social determinants of health – unmet social, economic, physical and environmental needs.

Dr. Michael Poku, senior medical director at Oak Street Health, said, "We have to ask patients and families, 'What do you require to be successful? I think I know what you need from a paternalistic perspective; you need to take this medication, you need this particular preventative intervention and you need to exercise.' But the big question becomes how we address underlying needs identified by [Maslow's Hierarchy of Needs](#). We want the patient to take their medication, but if they're busy addressing fundamental needs such as housing and food insecurity, we're not going to be successful from a medical perspective."

Effectively running a clinical trial including minority communities with income challenges requires assessment of these underlying issues: Do they feel safe? Do they have enough food? Do they have childcare? Are they concerned about the money for extra bus rides to the clinic or perhaps co-pays? The effort begins during screening and identification. Historically, the industry felt this was not our domain; we focused only on health-related issues. We didn't talk about socioeconomic status, transportation needs or other factors

because we operated in a silo, and ancillary factors were someone else's concern. Today, however, we know how inextricably linked these concepts are. Clinical trial teams need to be aware of these issues and address them.

"Once you go out into the community, you have to take off your white coat," said Dr. Lisa Treviño, vice president of research and development for DHR Health. We need to take off our titles, badges and pedigrees. We must approach patients with accurate, transparent information about their disease, share knowledge they can understand, and then get them to talk and engage.

"In Hispanic communities, we have to remember that healthcare is a family affair," explained Treviño. "We are not only speaking to individuals with, for example, diabetes or fatty liver disease; we must also talk to the family. We need to include everybody and make them feel comfortable because these communities are all about family." Likewise, we must embrace their culture to successfully break through barriers to achieve better healthcare initiatives, including clinical trial participation.

This well attended and engaging [WCG Patient Forum event](#) emphasizes that, as an industry, we can work together to diversify clinical trial enrollment, retain minority patients and provide quality healthcare to underserved and vulnerable populations. If you're ready to increase diversity and equity in your clinical trials, WCG can help. [Contact us here.](#)

## RESOURCES

- [WCG Patient Forum](#)
- [Sickle Cell Disease Association of America \(SCDAA\)](#)
- [National Institute for African American Health \(NIAAH\)](#)
- [Patient-Centered Clinical Care for African Americans](#)



The WCG Patient Forum is a call to action for clinical research professionals and volunteers to drive the change we need now. This series of discussions with leading voices in patient advocacy and clinical research addresses obstacles and provides solutions that can be put into practice today.

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