As an industry, we must recognize and address a complex problem: racial and ethnic minority populations have historically been underrepresented in clinical trials. Over time, it has become widely recognized that this issue is a systemic problem, not a participant one. What does that mean? It means there have been limitations in clinical research that aren’t isolated, but deeply embedded in our processes and systems. These limitations can include anything from protocol complexity to a lack of diversity in the clinical research field, which can create barriers to ensuring participation. This can have long-term implications for equitable access to medicines.

We’re making progress. In the past few years, Merck has increased participant diversity in our trials. Much of our progress is thanks to our community collaborators, whose engagement is vital in helping us understand and solve the complex issues at play.

Defining community collaborations

For me, community is synonymous with home. I grew up in Selma, Alabama. Many consider it the seat of the Civil Rights movement, but it is also the small southern town that taught me the power and importance of community.

At Merck, I’m a Diversity Program Lead for Clinical Trials, and part of my job is working directly with community-based organizations and leaders to provide valuable resources about clinical research. I also help our company and communities make connections to try to improve trial access. An important step for increasing clinical trial participant diversity is helping to ensure everyone can make informed decisions about their health, no matter who they are or where they live. That starts with education.

Over my years in the industry, I’ve learned something valuable from every person, project, and community. Some of my takeaways include:

- Learning never ends. Every engagement helps improve our understanding of how an organization operates, the unique needs of a particular community, or what approach would be most impactful. We need to listen.
- Start with the community-based organizations. They are the most knowledgeable about what their community needs. In addition, they are connectors and can be a bridge to valuable resources, insights, and additional partners.
- Each community is unique, with its own set of challenges and strengths. For example, the needs of an African American community in the Bronx are different from one in rural Alabama—we cannot retrofit strategies from one to the next. It is important to listen and learn about the particular needs of the community.

Building trust

Being a good collaborator starts with trust. Without that, we can’t build a path forward. It’s the foundation to everything else, but it can be the hardest part to get right.

I’ve found the best way to earn trust is by listening. We want to ensure our partners feel heard—especially because we use insights from them to build our approach. It’s also important to ensure we’re not guided by preconceived ideas about what they need. If you ask what needs to be done, the community will tell you.

At Merck, we recently established a U.S. Community Advisory Panel, with patients, caregivers, health care providers, and community members from diverse backgrounds who—along with our existing Patient Advisory Panel—share insights that help us incorporate the patient perspective in our sites and patient engagement methods. We listen to them, and we learn a lot.

The best part is that we are seeking their guidance early, when it can have the greatest impact. For example, they are helping us design our protocols to be patient-friendly by reviewing the number of in-person site visits and inclusion/exclusion criteria for trials. That way, we’re able to address potential barriers as early as possible in the process.

Putting people back into collaborations

Too often, we forget that collaborations are about relationships, and those are built between people who trust each other. People are also the focus of our trials. When we make our efforts more about people, we must also think bigger than trials and focus on wraparound care like disease education and screenings. There are still many who are not aware that they may be eligible for a clinical trial. It’s important that we prioritize education and awareness, long before there is a study to enroll in.

We can only earn trust as a collaborator in the continuum of a community’s health care. Our support can’t be exclusive to one-off projects. We must be present and active in what we help build.

Most importantly, we must remember the thread that runs through it all: the real definition of the word ‘community’—people.

There is a critical need for more inclusive participation in clinical research. Learn more from a diverse and inspiring community of clinical trial volunteers at medicalheroes.org. 

Together we can make a difference.