

Physician Roundtable: Diversity in Clinical Trials

Participating Physicians



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Infectious Disease Specialist at Ascension DePaul Community Health Centers of New Orleans



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CEO/President of Bay Pointe Behavioral Health Service, Inc., and South East Houston Research Group, Houston, TX



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SVP, Chief Community Impact Officer, Ascension CEO and President of Ascension Providence Health System



Michael G. Griffin

CEO and President of Ascension DePaul Services of New Orleans & DePaul Community Health Centers

COVID-19 is disproportionately affecting people from minority communities. As a recent [article](#) highlighted, among the 350,000 people who have registered for these clinical trials, only 10% of participants are Black or Latino. This is a staggering figure given that more than half of the reported cases in the U.S. have been among Black and Latino populations.

As bringing research to these communities was challenging prior to the pandemic because electronic health record (EHR) data used to identify patients does not disclose demographic information, it is difficult to track patients for inclusion. With the lack of trust minority communities extend toward the clinical research community, especially due to the Tuskegee study and the unethical treatment of Henrietta Lacks, truly inclusive research still has a long way to go.

Elligo's medical director and vice president of medical affairs, Dr. Faith Holmes, and Tina Locke, senior healthcare partnerships specialist, sat down (virtually) for a roundtable discussion with physicians across our network to tackle the issue of diversity in clinical research.

What does “diversity” mean to you as it relates to clinical research?

Dr. Greene

Diversity means many different things. It includes a person's race, ethnic background, and their socioeconomic status, but it also relates to where people live. Because of the social determinants of health, where people live can affect how they adhere to their healthcare as well as their culture, and even what they believe.

Dr. Duperval-Brownlee

Certainly, there are many opportunities that are articulated in all of the classic dimensions of diversity. There's a lot of well-deserved and much needed credence given to race and ethnicity as of late, but also certainly as it pertains to age and socioeconomic status, and the recent pandemic has articulated that much more. Beyond diversity in subjects, however, there should be strong strategies for inclusion, for researchers, sites of trials, patient populations.

Dr. Broussard

It's important that research projects reflect diversity in the participants and the researchers. These two project features should be intertwined to address recruitment of subjects. We're going to be challenged by recruitment among African Americans in particular, because there's a great deal of mistrust in the African American community around research in general. Study participants will be able to better relate to researchers of color, who are familiar care providers.

How does diversity benefit the healthcare community and the patient?**Dr. Duperval-Brownlee**

Diversity provides clinicians with informed direction and guidance to ensure that medicines that are available on the market are equally safe and effective for all the populations. If the diversity isn't present in the research and in the trials, then there is no assurance to the patient that the treatment is going to work or that they'll have access to it, because, frankly, there's not enough evidence.

Mr. Griffin

Diversity informs what we do from a policy standpoint, from a resource standpoint, and from a health equity standpoint. If the healthcare community in general works to increase inclusion and diversity on all of the previously mentioned fronts, coupled with empirical data to measure overall effectiveness, resources would be better spent to improve equity across the board.

How important is patient outreach within diverse populations?**Dr. Miller**

In Baltimore City, we have a very diverse population. But we always have trouble with inclusion, and it's always a challenge to meet and maintain that diversity. It's going to be a struggle, especially given the mistrust is even greater given all the politics surrounding vaccines right now.

Dr. Higgins

Researchers fail to see that the person in front of you is not always the person making the medical decisions regarding their own health. In Black communities, many people go back and talk to their mom, grandma, siblings, or may even talk to a preacher, realizing that over 80% of Black people go to church once a week and that almost half go to church twice a week. Involving the other people making those decisions is important, and it's equally important to have them participate.

Dr. Greene

The key here is trust. Because of the Tuskegee experiment, a lot of African Americans don't trust clinical research and science. If you can reach out to trusted pastors and partner with the church in the community, or even those local community leaders, that would make people more trusting and willing to participate in trials.

Mr. Griffin

Patient outreach serves as a critical component for effectively connecting with diverse populations, especially persons in underserved communities, many of whom are adversely impacted by various social determinants of health. These individuals struggle with food insecurity, lack of employment and sufficient housing, and other challenges. Oftentimes, these issues must be addressed in addition to taking care of their health. It is important for clinical researchers to account for these factors when attempting to accurately assess diversity in healthcare.

Dr. Duperval-Brownlee

Patient outreach is very important, and not just at the time that organizations need something from the community. The work of community engagement is a long and persistent journey. With this work, organizations can learn those barriers to recruitment and enrollment, and even some of the healthcare access inequities that could go along with it. Without, it just builds to unknowns which contributes to lack of trust, you know, for people to be engaged. For some, it'll be easier to overcome than others.

What are some of the limitations of electronic health record (EHR) data used to identify diverse patients?

Mr. Griffin

Each electronic health record system (EHR) possesses strengths and weaknesses in terms of the data that is produced. Most EHRs do not particularly capture or account for social determinants of health. There could be environmental and social factors that limit an EHR's ability to fully assess a given population. Another challenge or limitation surrounds codes that are utilized for accurately assessing social determinants, which are not as comprehensive as methods used in clinical coding.

Dr. Duperval-Brownlee

The EHR captures what it's fed. Hopefully the record is able to capture not only critical, basic information for patients, but understand demographics and other factors that impact health. In thinking about the early work that I led in our system, we weren't consistently capturing information that might contribute to a social vulnerability index until recently. The pool of people that you're looking for might not even be captured because they haven't been included.

Is there potential for additional outreach opportunities in these communities?

Mr. Griffin

Indeed there are additional outreach opportunities in these communities. Many entities such as the National Urban League and the NAACP are well entrenched in these communities and are highly respected and trusted by the people whom they serve. Historically black colleges and universities (HBCUs) like Xavier University of Louisiana and Dillard University in New Orleans are similarly positioned. Additionally, healthcare entities should consider performing community service such as investing in an educational series with community leaders. In a nutshell, a certain level of trust must be established prior to working with these communities.

Dr. Duperval-Brownlee

Absolutely! Outreach is really about the long play of community engagement and, frankly, it's something that healthcare providers and communities struggle with. I know from experience, that even within our own organization, that we've struggled at it. We've learned that a best practice is for organizations to become a long-term partner in the communities that you want to be entrenched in. The faith community is extremely important, especially for some demographics, as the church has had critical roles in meeting the gap in social needs for many communities.

Is there anything else you would like to share, either in terms of how Elligo's model helps or could help more in increasing participation or representation?

Dr. Miller

Baltimore includes large Hispanic, Burmese, and Arabic populations, so it's important for us to have all the information available in multiple languages because we always want to have handouts in people's native language. Elligo could help push for that representation across their sites depending on the local population.

Dr. Greene

Elligo's approach is a good way to increase diversity. Like I said, the keyword is trust, and DePaul was already trusted in the New Orleans community. Patients trust their providers at DePaul because a lot of providers are minorities, they're African American, they're Hispanic. The partnership with physicians helps increase diversity because it shows patients that we endorse this trial, and we want to encourage you to participate in it. We trust what's going on and we've demonstrated that we care about you as a patient.

Dr. Broussard

Through Elligo, DePaul is launching a more aggressive research effort. Elligo is experienced, and I'm looking forward to learning from them. I've already learned a great deal.

Mr. Griffin

I believe that the Elligo model's biggest attribute is that it gives smaller entities and agencies more opportunities, resources, and expertise needed to participate. Oftentimes, entities and agencies located in rural areas do not possess the resources or have access to the expertise that is needed in this regard and are not partnered with an academic institution. Elligo makes it easier for that patient base and population to participate, which is a part of what clinical trials and studies desire: the diversification of the work. Elligo is a great concept, and what is being put forth is greatly needed. Entities such as the National Urban League are very interested in supporting clinical trials that accurately capture and present data about the communities they serve. Finally, consider partnering with entities that do not regularly conduct this type of work. This could possibly open doors for your expertise to be used by them.

Dr. Duperval-Brownlee

I have appreciated our relationship with Elligo and the unique role that it plays. Being able to share and listen is very important in establishing a high level of trust and, so far, my interaction has been both inclusive and informative. From the first conversation, describing that on a local level, especially when you're trying to recruit, some of the barriers to identification and that leadership, PIs, and directors can actually do this, and it's not the usual competency that you might find in a clinical setting. Having that capacity to be able to train and identify people who can help fulfill that role removes the barrier.

I want to add to that because Elligo could develop a whole new layer of advocacy that this proposition of equity is really helping all of the people who may need therapeutics, whether one is vulnerable or not. I think about our current state with the pandemic, certainly views around the COVID-19 vaccine, and social justice, and think this an opportunity to be advocates for a just and equitable society. By improving its health, we ensure that the therapeutics that are being developed are truly available to everyone who is entitled to have them.

About Elligo Health Research®

Elligo Health Research, a healthcare-enabling research organization, uses electronic health records and the trusted patient and physician relationship to ensure all patients have access to clinical research as a care option. Powered by our *Goes Direct*® approach and novel IntElligo® Research Stack clinical technology, our team provides access to the best healthcare experts, patients, and research technologies. We engage physicians and patients who otherwise would not participate in clinical research and accelerate the development of new pharmaceutical, biotechnology, and medical device and diagnostic products. Learn more at elligodirect.com.