



XPLORE RARE-X

## RARE-X Launches DEI Scoping Project

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For Teneasha Washington, the problem of diversity in rare disease advocacy and research is apparent anytime she attends a conference. "Typically, I will be the only person of color in the room," she said.

One rare disease organization approached her to do a study when they found that the registry they built consisted primarily of white women and their children.

"They didn't have information on other races and ethnicities. In order for you to have a representative sample, you can't just say, 'Hey, we're going to build a registry and put the registry out there,'" said Washington. "It's going to take some grassroots efforts and some community engagement and some relationship-building to make sure that that happens.

As RARE-X seeks to build an inclusive portal of patient-owned-data that represents the diversity of the rare disease community, it has named Washington to lead its diversity and inclusion efforts.

For RARE-X, that will also mean going beyond gathering data, building relationships with a range of communities, and establishing trust.

RARE-X will need to incorporate grassroots community engagement in the scoping study that Washington leads as part of its efforts. That will help build connections with those communities and provide an understanding of which questions within a data platform they don't feel comfortable answering, which questions may be missing for their particular population, and how RARE-X can incorporate that in the overall dataset.

"We want to make sure that when we think of diversity, it spans across the realm of diversity. That doesn't necessarily mean just black, white, or anything like that," Washington said. "One of the tasks we are embarking on is defining what that looks like for RARE-X's data platform and anything else that the organization wants to do in the future."

Washington, founder, and CEO of The Washington Group and an assistant professor at the School of Public Health at the University of Alabama at Birmingham will lead a scoping project exploring the state of rare disease data collection. Her particular focus will examine the extent to which it is demographically representative, provide insights into barriers that exist to making data sets inclusive, and provide a series of recommendations for RARE-X as it moves forward.

"RARE-X believes that if we remove barriers to access to best-in-class technology, with proper education, support, and governance, we will enable patients to securely and responsibly share their critical data, and become active participants in medicines development. And if we get this right, we will help change the landscape for rare disease patients," said Nicole Boice, co-founder and executive director of RARE-X. "Part of doing that requires us to ensure that what we are building will support the diversity of data that is reflective of the diversity of the rare disease community. This will include additional considerations in literacy, socioeconomic, access to technology, incorporating adaptive technologies, and most importantly, building trust."

The issue of diversity is not merely a matter of progressive chic but has significant consequences for healthcare data, particularly in the area of genetic diseases where the lack of diversity can lead to incomplete understandings or incorrect conclusions about therapies and diseases.

As a starting point, Washington wants to make sure that RARE-X thinks of diversity in the broadest sense and will be working on assembling an advisory board reflecting that diversity.



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