

Analysis of Strengths and Barriers of Engaging a Diverse Population in a Biobank Program

Danielle Despanie and Tayler Payton

Background: The All of Us research program is a nation-wide effort to build the largest public health data repository and biobank in the world, comprising biospecimens and multi-dimensional data from more than one million people across the United States. A major concern of clinical research is the lack of minority representation, which can bias study results and further perpetuate existing health disparities. To increase minority engagement and representation in this program, we must identify barriers within the program and effective engagement practices that can be used in different communities. To ensure diverse participation in the program, successful and sustained community engagement efforts are essential.

Aim: We examined the current engagement methods and the impact of communication between community partners and health provider organizations (HPOs) within All of Us.

Measures: We interviewed four distinct community partners and five staff members from two different HPOs. Two interviews were conducted per person and results were tabulated, comparing and contrasting HPO staff perceptions with community perceptions about communication effectiveness.

Recommendation: Our analysis emphasizes the need to effectively train diverse staff to engage and properly establish trust within the community, as well as provide the necessary resources to combat systemic issues such as a lack of transportation and computer literacy.

Conclusions: While our results show many strengths of the All of Us program, they also indicate that there remain significant community engagement barriers to overcome.