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Using Community Engagement to Enhance Quantitative Research in Transgender Health

Introduction: Transgender and gender-diverse (TGD) individuals experience high rates of discrimination in healthcare and are significantly underrepresented in scientific research. Seeking perspectives of the members of this community during research design can illuminate unique disparities and highlight community priorities. To inform our EHR data-only study examining cardiovascular health in TGD adults, we conducted a Community Engagement Studio.

Methods: Five LGBTQ+-identified participants from diverse backgrounds were recruited for a virtual studio where the research team presented their project and sought feedback. A transgender individual with facilitator training posed open-ended questions exploring risk factors for heart disease and stress, risks and benefits of gender-affirming hormone therapies, and reservations about scientific research participation.

Results: The workshop highlighted three major themes: 1) limited access to affirming healthcare, especially in the current socio-political climate of the American Southeast, likely contributes to stress and risk for heart disease, 2) the importance of intersectionality is often overlooked in research, and 3) concerns about researchers' motives and how findings may be presented limits participation in research. With this input, we made several changes to our data collection and analysis plan. As examples, we are using HIPAA-compliant de-identified health database to address privacy concerns and including covariates in our analysis that serve as proxies for racism, socioeconomic status and access to care.

Conclusions: Studio feedback provided insight into the lived experience of our study population, allowing us to prioritize the needs of the community itself and more accurately model relevant confounding, enhancing the relevance and quality of the research. Community engagement is underutilized in quantitative research; the impact of this studio on study design serves as an important example of how community input may shape even data-only research.