

Deaf ACCESS: Adapting Consent through Community Engagement and State-of-the-art Simulation

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One of the most severely underserved populations in the U.S. health system is the **Deaf community** – a sociolinguistic minority group that communicates using American Sign Language (ASL).

A recent ASL health survey found startling disparities in obesity, domestic violence, and suicide compared to the general population. Further research on these disparities is lacking due, in part, to researchers' use of **recruitment, sampling, and data collection procedures that are inaccessible to Deaf ASL users.**

Another barrier to Deaf people's research engagement is **fear and mistrust of the biomedical community.** Rather than recognizing Deaf people as a cultural group, doctors and biomedical researchers often follow the medical model of deafness, which aims to cure or fix hearing loss and, historically, has sought to eradicate deafness – an approach considered a form of eugenics among members of the Deaf community.

To address these issues of inaccessibility and mistrust, our community-engaged research team is conducting a two-year R21 study to **improve the research informed consent process for Deaf participants:**



Hired 4 Deaf Community Advisors



Hosted 3 Deaf Community Forums



Hosted 4 Focus Groups about Informed Consent



Produced a Training Video to Teach Hearing Researchers How to Work with Deaf Participants



Test Training Video in UMMS iCELS Simulation Center (Spring 2018)



Ongoing Dissemination to Deaf Community via ASL Videos

