Mar 9th, 8:00 AM

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

Melissa L. Anderson  
*University of Massachusetts Medical School*

Timothy Riker  
*Brown University*

Kelly S. Wolf Craig  
*University of Massachusetts Medical School*

See next page for additional authors

Follow this and additional works at: [https://escholarship.umassmed.edu/chr_symposium](https://escholarship.umassmed.edu/chr_symposium)

Part of the Civic and Community Engagement Commons, Communication Sciences and Disorders Commons, Community-Based Research Commons, Community Health and Preventive Medicine Commons, and the Translational Medical Research Commons

Repository Citation

[https://escholarship.umassmed.edu/chr_symposium/2018/posters/6](https://escholarship.umassmed.edu/chr_symposium/2018/posters/6)  
[https://doi.org/10.13028/yxkj-eq42](https://doi.org/10.13028/yxkj-eq42)

This material is brought to you by eScholarship@UMMS. It has been accepted for inclusion in Community Engagement and Research Symposia by an authorized administrator of eScholarship@UMMS. For more information, please contact Lisa.Palmer@umassmed.edu.
Presenter Information
Melissa L. Anderson, Timothy Riker, Kelly S. Wolf Craig, Kurt Gagne, Stephanie Halukin, Jonah Meehan, and Emma Pici-D’Ottavio

Keywords
Deaf people, deaf community, Deaf ACCESS, Adapting Consent, ASL, biomedical research studies, participation, training

Creative Commons License
This work is licensed under a Creative Commons Attribution-Noncommercial-Share Alike 3.0 License.

Rights and Permissions
Copyright the Author(s) 3.0 License

This poster is available at eScholarship@UMMS: https://escholarship.umassmed.edu/chr_symposium/2018/posters/6
Deaf ACCESS: Adapting Consent through Community Engagement and State-of-the-art Simulation

Melissa Anderson, Timothy Riker, Kelly Wolf Craig, Kurt Gagne, Stephanie Hakulin, Jonah Meehan, Emma Pici-D’Ottavio

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

This study is funded by the National Institute on Deafness and Other Communication Disorders (NIDCD), 1R21DC015580. Study procedures are approved by the UMMS Institutional Review Board.