



Research in the Works



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

The U.S. Deaf community—a sociolinguistic minority group of 500,000 Americans who communicate using American Sign Language (ASL)—is often not included in health research. Deaf people, however, constitute a high risk population who experience higher rates of obesity, domestic violence, and suicide than the general population.¹

While future health studies need to include Deaf people in their samples, most research procedures do not meet the needs of the Deaf community. For example, all human subjects' research involves an informed consent process, during which potential participants learn about research procedures, possible risks of being in the research study, and then decide if they would like to participate in the study. This information is usually communicated in written or spoken English, rather than translated into ASL, making the process inaccessible to the Deaf community. In addition, the Deaf community often feels mistrust toward researchers and strong resistance to enrolling in research studies because of the long history of mistreatment of Deaf people in the research world.²⁻⁴ Researchers must develop ways to improve access and build trust with the Deaf community to include this underserved and at-risk population in human subjects' research studies.

The overall goals of Deaf ACCESS are to:

- Increase and rehabilitate trust between the Deaf community and health researchers;
- Improve the abilities of researchers to include Deaf participants in their research studies;
- Increase the number of Deaf people who participate in research; and
- Expand the range of backgrounds and capabilities of research teams via the inclusion of Deaf people as team members.



Project activities include:

1. Gathering feedback from the Deaf community via community forums and focus groups. During these activities the team will learn about the Deaf community's experiences with health research and get suggestions for how researchers can do a better job at enrolling Deaf people in research studies. See our June 2017 publication and ASL video for more about the community forums completed in Phase 1 here (<http://escholarship.umassmed.edu/pib/vol14/iss6/1/>).
2. Developing a training program for researchers about recruiting and enrolling Deaf people in research studies, specifically on the informed consent process (Phase 2).
3. Testing and evaluating this training program with researchers who have not previously worked with Deaf individuals (Phase 3).

Our results will support a larger trial of Deaf ACCESS and will produce researcher training products for distribution and replication. This work will lay the foundation for a sustainable program of research that shifts how we approach and engage the Deaf community. Our long-term goal is to increase the number of Deaf people who participate in biomedical research studies, and encourage more Deaf people to become actively engaged in the research world.

Project Personnel: The Deaf ACCESS research team includes: **PI:** Melissa Anderson, UMMS; **Co-I** Timothy Riker, Brown University; **Deaf Community Advisors:** Kurt Gagne, Stephanie Hakulin, Jonah Meehan, Liz Stout, and Todd Higgins (former); **Research Coordinators:** Emma Pici-D'Ottavio and Kelsey Cappetta (former); **Intern:** Annie Prusky (former). **Funder:** National Institute on Deafness and Other Communication Disorders (NIDCD) 1R21DC015580-01. **Time Frame:** 07/20/2016 – 06/30/2018. **Study Contact:** Melissa Anderson: Melissa.Anderson@umassmed.edu

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