

STRIDE

Strengthening Translational Research In Diverse Enrollment

Welcome!

Welcome to the first e-newsletter for the STRIDE project. Strengthening Translational Research in Diverse Enrollment (STRIDE) is a research study with the goal of improving racial and ethnic minority recruitment in clinical trials. This project is a partnership between the University of Massachusetts Medical School, the University of Alabama at Birmingham and Vanderbilt University Medical Center.

Project Updates

Recruitment Training

Community members on the STRIDE team are helping to create a comprehensive training program to improve clinical trial recruitment. This training program will teach research assistants better ways of communicating with people interested in taking part in a study. The goal of this training is to make potential participants feel more comfortable when agreeing to take part in the study.

Electronic Consent

Community Members in Worcester, MA and Nashville, TN gave feedback about different pieces of electronic consent, including Avatars (animated versions of people) and videos to explain research procedures (like an MRI).

Community members recommended:

- Changing the look and voice of Avatars - Community members recommended Avatars should look like doctors and have realistic voices.
- Showing what it would be like, from start to finish, for someone to have the procedure and showing the doctor or study staff talking with the participant.

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Spotlight: Storytelling in STRIDE

For many people, choosing to participate in a clinical trial is a big decision which can be scary. Hearing firsthand about someone else's experience in a research study, might help a person know what to expect from their participation. Knowing that another person has the same questions and concerns about a study can be comforting.



In the fall of 2017, the Storytelling Team visited both Birmingham, AL and Nashville, TN to record community members telling stories about their own experiences with clinical trials. The goal of these stories is help potential participants feel better making the decision about whether or not to participate in a clinical trial.

What is Therapeutic Misconception?

"No direct benefit to you as the patient or participant". Something like this sentence will show up on most clinical trial consent documents. Even after reading this, many people who take part in clinical trials still *feel* like the clinical trial will make them better.



This idea that participating in a trial will somehow help even if it likely will not is called "Therapeutic Misconception".

Clinical trials are designed to create broad knowledge that will help researchers to better understand a medication or condition. The study will not always help the people who take part in the trial. Joining the study without a clear understanding of this idea can lead to disappointment and frustration for participants. Many of the parts of STRIDE, like the training program and electronic consent features, are designed to decrease therapeutic misconception and help participants to understand the true risks and benefits of a clinical trial.

Looking Ahead

- Testing the tools in a real study at UAB
- Additional community feedback on avatars and videos
- Editing storytelling videos from Birmingham, AL and Nashville, TN
- Continuing to develop consenting training program

Meet Our Community Investigators:

Community Investigators at each site are working with the STRIDE team to provide feedback and recommendations on each piece of the project. Learn more about each of our Community Investigators below.



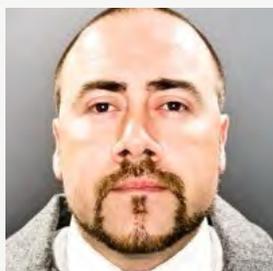
Fred Jenoure (UMass)

Frederick Jenoure has more than 30 years of experience in leadership positions with academic and health care institutions and community organizations. His professional experience includes management and organizational structures, diversity and inclusion, supervisory training, property management, conflict resolution, and union negotiations. He has served in a variety of leadership roles on the boards of nonprofit organizations in Connecticut and Massachusetts and received numerous service awards. In addition to STRIDE, he co-chairs a Community Advisory Board for UMass Medical School composed of community and corporate leaders.



Amancia Alvarado Carrera (UAB)

Amancia Alvarado Carrera has worked as a social worker assisting indigenous people rural areas in her native country, Guatemala. Some of her work experience in the United States includes community projects with the Catholic church and defending rights of immigrant workers. She has worked for several years with UAB on research projects that involve preventive medicine for Spanish speakers.



Daniel Cruz (VUMC)

Currently a financial professional with New York Life, Daniel has experience working with at risk teenagers and as a part of community outreach forums. After witnessing his grandmother's financial struggles, Daniel developed a desire to show families, that would not normally be approached, how to protect their family and their future. Through his work at New York Life, he seeks to be a resource to help underserved populations to enrich their family's future. Daniel serves as an active participant in Community Engagement Studios.



Clarice Davis (UAB)

Clarice Davis has a diverse background in community-based participatory work and is a 2009 retiree of Jefferson County Department of Public Health, in Birmingham, AL. She has 20 years of experience in Community Health and engaging communities as a Community Resource Representative. Post retirement, Clarice continues active work in community organizing, assessment and capacity building for local grass-root organizations.



Jackie Sims (VUMC)

Jackie Sims is a mental health professional with 15 years of experience in law enforcement as a crisis intervention specialist to victims of violent crime. She has worked with numerous grassroots organizations on issues of living wages, housing equity, barriers to employment, re-entry and homelessness. Her most recent work for the past ten years has been as a community organizer/activist. Jackie serves as an active participant in Community Engagement Studios.