



# Raising Research Study Participation of Underrepresented Minorities

*Miami CTSI engaged UM investigators to address challenges and barriers, strategies and best practices in a special webinar.*

Blacks and Latinos constitute about 32% of the U.S. population, but only 6% to 8% of all participants in federally funded clinical trials. The problems this poses for meeting study goals and applying research findings to different racial and ethnic groups are well understood.

On July 8, the Miami Clinical and Translational Science Institute (CTSI), in collaboration



with the University of Miami's Office of the Vice Provost for Research & Scholarship, the Miller School of Medicine's Office of the Executive Dean for Research, and the All of Us research program, hosted a webinar, "Recruitment & Retention Strategies for Underrepresented Minorities in Research," focused on practical means of meeting participation goals.

Four investigators from across the University of Miami offered the benefits of their experience: Victoria Behar-Zusman, Ph.D., associate dean for research in the School of Nursing



and Health Studies, Frank Penedo, Ph.D., director of the Cancer Survivorship Program at Sylvester Comprehensive Cancer Center, Margaret Pericak-Vance, Ph.D., director of The John P Hussman Institute for Human Genomics, and Olveen Carrasquillo, M.D., M.P.H., chief of the Division of Internal Medicine at the Miller School of Medicine.

Three prerequisites for success resonated through the presentations:

- The most successful recruitment efforts stem from engaging early and often with community leaders, and then with individual participants.
- To retain participants and extend recruitment avenues into the future, community engagement must be sustained beyond enrollment, with frequent touch points throughout the research study.
- The principal investigator must lead, not simply delegate these responsibilities.

“The Miami CTSI is dedicated to improving culturalized health science,” said Dr. Ralph Sacco, director of the Miami CTSI as well as senior associate dean for Clinical & Translational Science and professor and Olemberg Chair of Neurology at the Miller School of Medicine. “Our expertise in the recruitment and retention of under-represented individuals in translational research studies is helping to more rapidly bring treatment discoveries to communities where help is needed the most. Disseminating these best practices is critical to advancing this mission.”

## **Community Culture Key to Recruitment**

Recruitment starts with understanding the important cultural



values of the community. Typically, this involves early and frequent meetings with the community health spokespeople – the pastor of the neighborhood church, prominent schoolteachers, a *promotora de salud* in a Hispanic community or a community center director.

“We need to find out what makes trial participation meaningful, beneficial and accessible, but also what keeps people away,” said Dr. Behar-Zusman, who studies prevention of substance abuse, violence and HIV/AIDS, particularly in vulnerable Latino communities.

Dr. Pericak-Vance, who researches Alzheimer’s disease in African Americans, said, “We have to build trust with the community before we ask if they are interested in participating in our studies. We need to maintain the relationship and show that we care.”

Dr. Behar-Zusman added, “Start with asking the questions, and listen to the hard truth. Get their feedback on priorities, barriers to treatment in their communities and strengths of their community’s health network.”

## **Addressing Barriers Head-on**

Cultural memories of minorities used as guinea pigs may remain and deter many from research participation, and researchers believe it’s an issue that must be addressed head-on.

Dr. Penedo, who works with Hispanic prostate cancer patients on cognitive behavioral therapy interventions, faces these challenges in collecting biosamples.

“The stigmas they see as associated with health research include confidentiality, use of information, perceived



government involvement and tracking,” he said.

His challenges extend further, into cultural stigmatization of prostate cancer. He said probing depression and challenges in intimacy can be viewed as attacking masculine identity.

“Cancer can be seen as a weakness, but prostate cancer even more so,” he said.

To help defuse this, they talk about how common cancer is, and stress the confidentiality of all their information.

“We tell them exactly how the biosamples will be used,” Dr. Penedo said. “That insurance companies will not have their personal information, and how exactly the records are deidentified. We are also very clear about the trial process itself – explaining expectations, rights and responsibilities – and we ask them to repeat what we have said back to us.”

Addressing logistical barriers such as transportation and arrangements for child or elder care are more straightforward but can be equally challenging. Dr. Penedo said that access to technology can be a barrier, as well.

“Smart phones don’t mean great connectivity,” he said..

To succeed, research is showing, investigators must understand and assist with these barriers.

## **Intentional Recruitment Planning**

Each speaker stressed the need to put recruitment at the front of the planning process. Often, grant proposals include low or loose cost estimates for recruitment and retention, but costs of media, staff time, mailers and events all need to be budgeted for with specificity.



Dr. Carrasquillo, who co-directs the Miami CTSI's Community and Stakeholder Engagement, as well as the Hub's Participant and Clinical Interactions programs said, "Principal investigators think deeply about their detailed protocols, but recruitment may be an afterthought.

"It can't be," he said. "Ask yourself, up front, how much of your staff time you are going to spend on recruitment, what metrics you are going to use, how will you measure success? How IT-heavy is your recruitment plan? Is it community-based or facility-based? These differences influence strategy."

## **Strategies for Engaging New Participants**

Once the research team has engaged the community of interest, the panel suggests advertising on social media, print, TV and radio, and mailers, as the more common means of getting the word out. Ensuring these messages and study goals expressed in a culturally sensitive and lay friendly way, is key to positive responses.

Dr. Behar-Zusman said that identifying the best media outlets is not always obvious. "In some Hispanic communities, the radio stations most listened to may be out of someone's garage, not the mainstream stations."

Dr. Pericak-Vance said, "*Legacy* magazine is the most read journal in the local Black community, so we worked with *Legacy* as part of our community outreach campaign"

As clinical research studies proceed, continuing to engage with these leaders – and with every participant as a whole person, not a study "subject" – solidifies relationships and helps ensure retention.



This can include newsletters and mailers, but it should also have a personal touch. The panel recommends pairing participants with research team members who call to check on how they are doing, send birthday/ holiday cards, and personally update them on the study progress.

Surveys indicate that 74% of Americans would be willing to participate in a clinical trial if they were asked by someone they trust.

“Despite the barriers, people really do want to participate if we can make research meaningful for them and accessible,” Dr. Behar-Zusman said.

The Miami CTSI is available to support investigators across the University of Miami hub with expert consultations on recruitment strategies as well as other aspects of trial design, grant proposals and IRB approval. Visit their website [MiamiCTSI.org](http://MiamiCTSI.org) to learn more, or email [CTSIservices@med.miami.edu](mailto:CTSIservices@med.miami.edu).

Additionally, study teams can use [UMiamiHealthResearch.org](http://UMiamiHealthResearch.org) to feature their health research studies and connect and engage with volunteers who have signed up for the registry. Learn more [here:](http://miamictsi.org/researchers/research-tools/university-of-miami-health-research) [<http://miamictsi.org/researchers/research-tools/university-of-miami-health-research>] or email [umiamihealthresearch@miami.edu](mailto:umiamihealthresearch@miami.edu).

A recording of the July 8 webinar is available to watch on the CTSI’s video platform [here](#). Use your University email address to register for an account.



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