

Restoring trust in research by creating lasting relationships

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Distrust can lead people to put up walls. For communities of color, past abuses, such as the Tuskegee Experiment, left them wary of scientific research.

That distrust has been further fueled by the on-again, off-again relationship some researchers have offered these communities. Keen at first to engage them to gain data for their studies, some researchers disappeared once funding ran out, often without even informing participants of study results.

Such relationships of convenience left these communities skeptical about researchers' interest in their health and welfare, said Michelle Nichols, Ph.D., an assistant professor in the College of Nursing at MUSC, who directs the South Carolina Clinical & Translational Research Institute's Community Engaged Scholars Program.

Tearing down those walls and restoring trust is the goal of community-based participatory research (CBPR). Its tools of the trade, according to Nichols, are trust, respect and willingness to put in the time and effort to repair and build relationships with community members, in part by listening to and respecting their stories.

In a recent article on CBPR in *Stroke*, Nichols and Gayenell Magwood, Ph.D., professor in the College of Nursing, share their decades-long experiences breaking down walls of distrust and provide examples from three [stroke](#) initiatives that successfully incorporated CBPR.

Their article's biggest takeaway message: stroke initiatives that rely on academic/community partnerships should benefit not just the research team but also the community. CBPR provides researchers an opportunity not only to walk a mile in [stroke survivors](#) and caregivers' shoes, learning about their concerns, priorities and needs, but to partner with them to find solutions.

In CBPR, stroke survivors and caregivers are involved at each stage of the research process, from coming up with the research question to designing an approach to improve outcomes and sharing study findings

with the community.

Creating a safe space for storytelling

The CBPR approach aims to create a safe space in which stroke survivors and caregivers can tell their stories. Those stories have much to teach researchers and are more likely to be "heard" by other survivors and caregivers adapting to a post-stroke life.

"It just resonates better with people, especially other caregivers, if they can see and hear somebody who's been there before," said Nichols. "I can explain what a disease is like as a clinician and researcher, but I really don't know what it is like to live with that condition or disease because I haven't lived it. But they have."

Researchers need to create a safe and comfortable space for patients and caregivers to tell their stories, said Magwood, and learn to communicate their science in a way that will resonate with this audience.

"We have to really push our scientists and clinicians to step away from the jargon," said Magwood. "We do training around communicating the research in plain language."

Another way to build trust, said Nichols, is to show that you are not going anywhere, even if funding runs out. Community partners need to trust that researchers care about the partnerships and that they are not merely relationships of convenience.

"You have to put in the time, spending weekends and evenings," said Nichols. "You have to become a part of that community."

They have found that the more fruitful engagements with the community tend to have staying power.

"I'm fortunate enough to have a community grassroots organization that I've been partnering with for 20 years," said Magwood. "That's with and without funding. "We have grown together, and we feel comfortable that our relationship will last."

When researchers put in the time required for CBPR, Nichols explained, community members open up, providing a more realistic picture of what living with stroke is like. Researchers and [community members](#) can then work collaboratively to address the challenges faced.

"They give us detailed examples of what it's like, things that we may not have ever known without them telling their stories," she said. "They open up their entire experiences and are very vulnerable through the process. Their input gives us better insight into what we need to do as clinicians and researchers to help to bridge this gap in services and care."

Becoming part of the community

The dozen or so states that make up the stroke belt have worse stroke outcomes than the rest of the country, but mortality rates are highest in its buckle. South Carolina is part of that buckle.

While considerable progress in emergent stroke care had been made in this region in the past decade, Nichols and Magwood were keenly aware that there was no community-specific playbook or navigational tools for transitioning patients from hospitals and rehab back to their new post-stroke reality in their own communities.

Knowing that building trust and meaningful relationship with this community would take time, they took it upon themselves to address these issues by initiating programs that would provide much-needed education and resources.

Nichols' work with *Survive to Thrive: Living Well with Stroke*, an initiative funded by the Patient-Centered Outcomes Research Institute, focused on learning about the barriers stroke survivors faced as they tried to resume their lives. She brought together survivors and caregivers with primary care providers, members of the rehabilitation team and academic researchers.

"We wanted to know what the experience was like for them, what their needs and priority areas were, what was missing and what was falling apart in the system," said Nichols. The team worked together to address gaps in research, education and resource availability. The partnership continues today.

Like *Survive to Thrive*, Magwood's *Community Based Intervention Under Nurse Guidance After Stroke (CINGS)* research study was launched to listen to stroke survivors and their care partners. Doing so provided great insights into the barriers that made it difficult for them to resume their lives. They then tested a community-engaged intervention and created a resource—*My Guide to Living With and Preventing Stroke*—to help them to navigate post-stroke life and to avoid a second stroke.

They point to these initiatives, which served to build the foundation necessary for trust and future engagement and forged lasting relationships that strengthened both the members of the community and the research teams, as positive examples of CBPR.

The future of CBPR

Based on results thus far, Nichols and Magwood are convinced that CBPR is a tool that can aid research across the globe. Sub-Saharan Africa provides one such opportunity.

Currently, Nichols is an investigator on several global CBPR studies addressing health disparities faced by under-resourced communities. One example is the Stroke Investigative Research and Educational Network (SIREN), the main goal of which is to estimate the burden of stroke in in this region. Many who experience stroke there do not have access to emergent stroke care or rehabilitation. Prevention and education, she said, are the best ways to protect the population, underscoring the fact that, regardless of geography, many of the same principles of mistrust and the need for relationship building apply.

While each CBPR initiative is unique, the principles are still based on the needs and strengths of a specific community, allowing CBPR to succeed anywhere, said Nichols.

"You can use the CBPR approach regardless of whether it's a geographical population or a population that has a particular health condition," she said. "It really doesn't matter whether we're talking about the Southeastern part of the U.S. or Europe, Asia or Africa—the same basic CBPR elements apply."

More information: Michelle Nichols et al, Crafting Community-Based Participatory Research Stroke Interventions, *Stroke* (2022). [DOI: 10.1161/STROKEAHA.121.035306](https://doi.org/10.1161/STROKEAHA.121.035306)

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