

## Editor's Note

What would it look like if community-based participatory research were the norm, not the exception, in graduate education? Keisha Ivey and her fellow authors of this featured Community Perspectives submission demonstrate how bringing diverse individuals together to collaborate, identify needs within communities, and then tailor research design and implementation strategies best to address those needs is a valuable training tool for the next generation of scholars.

The authors identify language, trust, and access not only as essential principles of their project implementation, but of their collective project learning, one involving faculty, students, and community. In order to successfully interface with lay communities, Ivey and her colleagues remind us, there needs to be a shared language—one free of jargon. Shared languages facilitate trust. Trust is critical, as Ivey and her team point out, to gaining access to typically hard-to-reach community members and research participants.

The benefit to the project team afforded by a community-based participatory approach is thus the privilege of actually effectively reaching those the work intends to effect. This benefit is catalytic; it produces, Ivey and her colleagues note, more meaningful understanding of community needs and assists in tailoring more culturally appropriate research endeavors.

Moreover, it is also generative. It broadens the learning horizons to include varied and creative ways of formulating research questions. What more important goal could we set for graduate education than that of learning to unlearn what we think and know? What more important skills could our graduates acquire than those involving negotiations of language, trust, and access? As Ivey's team makes clear, these skills are what allow us to learn from an education confined not to instruction in the classroom, but informed by experiences lived beyond our ivory towers.



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# “All Voices Matter”: Perspectives on Bridging the Campus-to-Community Gap

Keisha D. Ivey, Kaleb Murry, Deanna Dragan, Marcus Campbell, Jacqueline Maye, and Christopher Spencer



Keisha D. Ivey

## Introduction

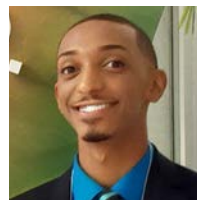
Project Sharing Opinions and Advice about Research in the Deep South (SOAR) aims to increase the involvement of community members to enhance the importance, relevance, and cultural appropriateness of disease research and interventions offered in the Deep South. SOAR recruits and trains community partners to include them in conversations about how best to identify and address mental and physical health disparities. Additionally, SOAR underscores the importance of addressing issues faced by ethnically diverse and underserved community members.

## Project SOAR

To date, SOAR has provided a foundation for better patient-centered outcomes by opening up new, and broadening preexisting, avenues for scientist/community collaboration wherein university and community partners share power and fulfill the goal of implementing culturally competent research within a community context. Conversations among community members and our academic partners have revealed a significant need for research specifically tailored to environmental justice/ecological health and chronic illness education in rural areas (e.g., diabetes and HIV). More specifically, community/academic partnerships are necessary to facilitate change and create the most nurturing environments possible for residents within each community.

Project SOAR has recruited, trained, and maintained community action groups in two under-resourced communities in Alabama—Holt in Tuscaloosa County and rural Sumter County. The community members are primarily African American men and women, with one Caucasian

woman participating. These individuals range in age from 33 to 77. Community members have been trained to work collaboratively with academic research partners both within and outside the academy to respond to the communities' place-based concerns. For the Holt community, these concerns have centered on ecological health and environmental justice and limited access to healthy and sustainable food and water due to a variety of environmental toxins. For the Sumter community, concerns have centered on diabetes and other chronic health conditions and enhancing resources available at a small rural hospital. Across both community projects, committee members provide useful, directive, and relevant feedback on recruitment fliers, survey items, and intervention components to be used within their contexts. Moreover, they facilitate dissemination of important research opportunities and findings to community members. They also serve as networking bodies, putting research partners in contact with potential study participants or other partners in the community. The voices following reflect the lived experiences of students and community partners as they actively engage in the project.



Caleb Murry



Deanna Dragan

## Student Perspectives

*Kaleb Murry and Deanna Dragan*

As graduate research assistants, we have worked primarily with the Holt in Action Committee. Our experiences with the Holt committee have reinforced the value of community perspectives on community research. With each research presentation, community members give thoughtful and beneficial feedback to the

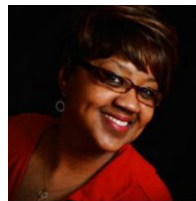
researchers who have assisted the projects in various aspects of community engagement. We believe that this type of feedback is a valuable part of research, especially within small communities. It is essential that researchers take the time to engage with these community members. Each of the project partners has received helpful feedback from the committee that has contributed to more easily understandable and more engaging project materials.

In addition to the unique research experience that we receive from being a part of the team, we feel we have an increased knowledge and understanding of local community issues and a deeper understanding of community dynamics unique to this area. As newcomers to Tuscaloosa, we are grateful for this understanding because conducting research in a community that you are unfamiliar with feels quite disconnected and it has really highlighted the importance of understanding the context and environment in which you are conducting research. Hearing the firsthand accounts of the eco-health issues within their community is an experience that allowed us greater insight into the topics that are most important to underserved communities. During our initial visit to the community meetings, we felt welcomed and encouraged to participate by the SOAR team members as well as the community members. As young researchers, participating in this project has influenced the way we think about recruitment in research studies and the extent to which psychologists communicate with jargon and terminology that is unfamiliar to community members.

The process between the researchers and committee members has been interesting and valuable to observe and participate in. There is a sense of excitement during discussions and that passion lingers even after the meetings have concluded. We have enjoyed watching the group dynamics transform from the first session to the most recent. We think the communication style between committee members and the SOAR team has become

more comfortable and open. Additionally, it seems to be one of the most well received research presentations about eco-health and environmental justice. The members seemed significantly more emotionally invested in the topic. This is a credit to the SOAR team in identifying a major interest of the members and bringing in a speaker on that topic. The SOAR team views reciprocity as vitally important to sustaining great relationships with the members. It is time that psychologists and other professionals were more attentive to the reciprocity of working with a community rather than treating them only as participants to further their own careers.

Overall, being on the SOAR team as a graduate student has shaped our approach to research. The meetings have been inspiring, fulfilling, informative, and productive. It is our hope that more graduate students will have more opportunities to get involved in community-based projects and that more projects like this will be initiated across the country.



Jacqueline Maye

### **Committee Member Perspectives**

*Jaqueline "Jackie" Maye,  
Holt in Action Committee*

I came to know about Dr. Rebecca Allen's project SOAR through another project I was working on through Holt in Action. These meetings have given the members of our community a venue to talk about our concerns on health and safety and the SOAR team has shared what other communities have done in our situation in both printed articles and videos. We've had speakers to come to each meeting on subjects we've chosen and it's been a wonderful learning experience.

During our monthly meetings the community members from different organizations, locations, generations, and backgrounds have the opportunity to fellowship and share current events and news. I look forward to the positive changes and how we as community members will be a part of them, and how our participation will make a difference for Holt through educating not only the advisory board [but also how] we can now share what we've learned with our community.

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Marcus Campbell

*Marcus Campbell,  
Sumter Community Committee*

Project SOAR has allowed us to bring a diverse team together to discuss what works best for our people in Sumter County. Exploring different ways to get health education messages out, maximizing the media and redefining the importance of regular visits with your health care professional are some of the objectives of the committee. Project SOAR is right on time for our county—it's exactly what we need. Health and wellness are essential for a great quality of life. Serving on this committee has been encouraging and I'm gaining such valuable information. As a citizen, I value hearing varied perspectives from other citizens in other counties, and our meetings consistently reinforce the notion that health and well-being is a priority. There are many challenges in Sumter, and I'd venture to say health education and advocacy is a top priority.

Now that it is being reiterated and reemphasized regularly in our meetings, we, as community action members, are reiterating and reemphasizing that information within our community, and people love it! For example, we had a

speaker present on the various consequences of diabetes and restricted or abnormal blood flow. I have a family history of diabetes and so do the majority of other committee members and we didn't know this information previously because the resources for that level of education aren't here. As members gain this knowledge, as well as further our resources, we can share that with our other community members, and I don't think my family or other community members would accept that information if it wasn't coming from me—like if it were coming from a doctor or a university or academic professional. I used to work in pharmaceutical sales, and we would have to go work in various regions.

If I learned one thing, it's that what works in Boston doesn't work in Tuscaloosa, and what works in New York may not work in York, Alabama. People here only trust people they know and can relate to, and I think the way information is currently delivered serves as a barrier. The way people talk to each other is so important and we don't talk the same way as folks do in Tuscaloosa or in Boston, so we can't assume that the same issues exist in each place or that the solution will be the same in all of those places. Sumter is an area where there are different challenges regarding things like income; it's different here than the living there, the industry is different, and there is little to no job security. People here don't have the money, the means to travel, or the insurance to get to a professional or to get a proper diagnosis so they're going to try a home remedy. Project SOAR is helping to combat that and is getting the word out about clinics and resources we have available.

In today's society, there is no way, especially in a small county like Sumter, to operate without a partnership like the one we have because of SOAR. Working with a university gives Sumter the opportunity to discuss and communicate that things that work in Boston or even Tuscaloosa will not work here. It allows us to tell our story, and it helps us identify

and meet the needs of our citizens. It will let us take the things that do work in other places and adapt them to fit our needs. The research team and other partners have allowed the committee to lay it out on the line—what we need—and so folks in Sumter feel respected and they are working with them. For example, we have ongoing discussions about language. Language is something that needs to be addressed and discussed early on. You have to know who you are trying to identify with. This is great research, but you want to make it comfortable for whoever you're working with and language is the engine that's going to make that vehicle run. In our meetings, language barriers were one of our very first discussions. Putting the right language out there for citizens to identify with. You're not going to use a complex word with a 98-year-old who's been hearing something different for their entire life. We want to make sure when we advertise things that it's accessible to everyone and catches everyone's attention. It's important for folks to understand what you're trying to say if you want them to do things like get their blood pressure checked. Some language barriers might even be different on the southern part of Sumter County and that's why we have a group of citizens from all over.”



Christopher Spencer

**Academic/Community Member  
Liaison Perspective**

*Christopher Spencer,  
Academic/Community Member Liaison*

I work closely with campus units and community partners in fulfilling the university's mission, which focuses on teaching, research, and service. I was approached by Dr. Rebecca Allen over a year ago to serve on the senior leadership team for SOAR. One of my main functions as a member of the team was to assist in the recruiting

of community partners to serve on the committee. Therefore, after the team selected the areas in which we wanted to form action committees, I immediately made contacts with residents and community leaders in both Holt and in Sumter County. We were very successful in recruiting a diverse group of members in both areas and I'm very excited about what I'm witnessing in SOAR.

I have seen community experts pouring their hearts and thoughts out to students, faculty, and staff members from The University of Alabama. They have not been shy about sharing their opinions and advice about research with the University research team and other professors. The members have made great suggestions and their voices have been heard and valued by researchers. I have also witnessed the development of our graduate students as they have left campus and traveled out in the community to participate in these committee sessions. I've worked with several projects in my nine years at The University of Alabama, and I can truly say that this is true community-based participatory research. The students, faculty and staff are learning from the community partners and the community partners are learning from researchers. I think everyone has been transformed and now understands that all voices matter in conducting research!

**Conclusion**

Overall, there was agreement among project members that SOAR has broadened the scope of research questions being asked in the academic setting and has provided new avenues by which community members can go about addressing their community's needs. This collaboration is an iterative process; the community makes their needs known to researchers who then formulate questions and a plan by which to conduct the research. This plan is presented to community members, who give innovative and practical feedback. This process brings all community voices together bridging the campus/community gap, and it increases the relevance and efficiency of research to ensure that community needs are identified and addressed.



## Bibliography

In putting together this report, the authors were informed by the theories and practices of many well-known community-based participatory research documents, including the following:

Bush, S.S., Allen, R.S., Heck, A.L., & Moyer, J. (2015). Ethical issues in geropsychology: Clinical and forensic perspectives. *Psychological Injury and Law*, 8(4), 348–356. doi:10.1007/s12207-015-9242-2.

Brulle, R.J., & Pellow, D.N. (2006). Environmental justice: Human health and environmental inequalities. *Annual Review of Public Health*, 27, 103–124. doi: 10.1146/annurev.publhealth.27.021405.102124.

Centers for Disease Control and Prevention. (2010). Social determinants of health among adults with diagnosed HIV infection in 20 states, the District of Columbia, and Puerto Rico, 2010. *HIV Surveillance Supplemental Report*, 19(2), 1–28.

Centers for Disease Control and Prevention. (2014). Estimated HIV incidence in the United States, 2007–2010. *HIV Surveillance Supplemental Report 2012*; 17(4).

Cook, W.K. (2008). Integrating research and action: A systematic review of community-based participatory research to address health disparities in environmental and occupational health in the USA. *Journal of Epidemiology and Community Health*, 62(8), 668–676. doi.org/10.1136/jech.2007.067645.

DeHaven, M.J., Gimpel, N.E., Dallo, F.J., & Billmeier, T.M. (2011). Reaching the underserved through community-based participatory research and service learning: Description and evaluation of a unique medical student training program. *Journal of Public Health Management and Practice*, 17(4), 363–368. doi: 10.1097/PHH.0b013e3182214707.

Ford, J.G., Howerton, M.W., Lai, G.Y., Gary, T.L., Bolen, S., Gibbons, M.C., Tilburt, J., Baffi, C., Tanpitukpongse, T.P., Wilson, R.F., Powe, N.R., & Bass, E.B. (2008). Barriers to recruiting underrepresented populations to cancer clinical trials: A systematic review. *Cancer*, 112(2), 228–242. doi: 10.1002/cncr.23157.

Foster, P.H. (2007). Use of stigma, fear, and denial in development of a framework for prevention of HIV/AIDS in rural African American communities. *Family & Community Health*, 30(4), 318–327. doi: 10.1097/01.FCH.0000290544.48576.01.

Institute of Medicine (2011). *Public engagement and clinical trials: New models and disruptive technologies: Workshop summary*. Washington D.C.: National Academies Press.

Israel, B.A., Schulz, A.J., Parker, E.A., & Becker, A.B. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health*, 19(1), 173–202. doi: 10.1146/annurev.publhealth.19.1.173.

Jones, L., Crabb, S., Turnbull, D., & Oxlad, M. (2014). Barriers and facilitators to effective Type 2 diabetes management in a rural context: A qualitative study with diabetic patients and health professionals. *Journal of Health Psychology*, 19(3), 441–453. doi: 10.1177/1359105312473786.

Kaiser, B.L., Thomas, G.R., & Bowers, B.J. (2017). A case study of engaging hard-to-reach participants in the research process: Community advisors on research design and strategies (CARDS)\*. *Research in Nursing & Health*, 40(1), 70–79. doi: 10.1002/nur.21753.

Spears, E.G. (2014). *Baptized in PCBs: Race, pollution, and justice in an all-American town*. Chapel Hill, NC: University of North Carolina Press.

U.S. Department of Health and Human Services (2014). *Healthy People 2020 leading health indicators clinical preventive services*. Retrieved from <https://www.thecommunityguide.org/resources/healthy-people-2020-leading-health-indicators>.

## About the Authors

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