

Community Partnerships Are Critical in Cancer Prevention and Control Research

Background:

The Centers for Disease Control and Prevention (CDC) funded the creation of the Cancer Prevention and Control Research Network (CPCRN) in different locations around the United States to encourage the adoption of cancer-related dissemination & implementation (D&I) knowledge. Through comprehensive programs, the CPCRN works with underserved communities to reduce health disparities related to cancer. Eight CPCRNs, including the South Carolina Cancer Prevention and Control Network (SC CPCRN) at the University of South Carolina, are funded by CDC. The SC CPCRN has functioned inside the CPCRN since it began in the early 2000s. The SC CPCRN was started as an arm of the South Carolina Statewide Cancer Prevention and Control Program (CPCP, 2003). The SC CPCRN was first funded by the CDC and the National Cancer Institute (NCI) to study the disparities in cancer rates between African American and European American populations. Early funding focused on the disparities that rural

communities experience. Racial differences in cancer and mortality rates have declined over time in South Carolina. However, disparities continue, requiring dedicated work from academics, professionals, community advocates, and policymakers.

The SC CPCRN is proud of its decades of work in cancer prevention and its dedication to preventing cancer and its related morbidities through communitybased participatory research (CBPR) methods. The SC CPCRN engages partners in all of its work through program partnerships like the South Carolina Witness Project. Every step of the research process, from original planning to shared dissemination, has been influenced by the SC CPCRN's community involvement, advisory boards, and established links with African American and rural communities. The recurrent loop model, which is referenced in Figure 1, is an illustration of this concept. It demonstrates the practical application of feedback and improvement at all stages of the cycle, promoting public health innovation that helped improve South Carolina's cancer-related outcomes.

This project aims to describe the various partnerships that the SC CPCRN has established over the years and to comprehend the frameworks that sustain these crucial connections for the development of the SC CPCRN's operations.

THE SC CPCP RECURRING LOOP MODEL®



Figure 1. SC CPCP Recurring Loop Model

What We Did:

Consistent with community engagement, the SC CPCRN held focus groups to study the center's evolution over time and its ongoing collaboration with community partners. Focus groups with program managers (N = 2) and current and previous faculty (N = 10) were held. The groups were asked questions like "Looking back, tell me about some of the strongest community partnerships that were generated



through CPCRN" and "How did the principles of CBPR shape your approach?" to identify what supported the community partnerships that form the foundation of much of SC CPCRN's work. These discussions were recorded and then transcribed (typed out) for study. Letters of support and other materials from the grant applications were gathered over throughout time.

Researchers used an approach to find and code patterns in the focus group discussion data. To best capture and describe the responses gathered, they analyzed the data using individual comparisons, reflection, code identification, and agreement. The research team found themes in the responses. After coding these themes, the team used Microsoft Excel to look at frequencies of responses. All participants received a summary report from the research team, along with the chance to share and clarify.

What We Found:

Half of the SC CPCRN relationships were participating organizations. General healthcare organizations made up the largest portion (35%), followed by public health (15%), cancer (15%), and oncology healthcare (15%). Other partnerships included community leaders and mini grantees. Five major topics were seen: 1) continuous dedication to community partners; 2) a focus on genuine relationship development; 3) celebrating community members' knowledge; 4) creating initiatives that benefit everyone; and 5) fostering a climate of cooperation from research to dissemination. Each is described in more detail below.

Continuous dedication to community connections. As one investigator explained, "We have a history of being community based, so our partnerships reflect that value. The community recognizes

we care, and we have had a longstanding commitment." The SC CPCRN's leadership intentionally created a framework that helped collaborations flourish through overlapping projects and activities. Through their teams' existing networks, the SC CPCRN continued to work on cancer prevention and control programs even when they were not formally supported. These networks included the SC Primary Healthcare Association, federally qualified health centers (FQHCs), and the SC Cancer Disparities Community Network (funded by NCI). These networks helped the SC CPCRN continue their efforts. to reduce cancer disparities in the state by forming important relationships. Interestingly, the SC CPCRN was among the first groups to include community partners in federal programs and other grant opportunities. According to another researcher, "many of us had individual research projects that all leveraged across these partnerships,

and all shared a commonly woven thread that really weaved a fabric of connectedness and collaboration that helped contribute directly to our success."

Developing genuine relationships. Knowing that many communities are wary to partner with researchers due to wrongdoings or betrayed trust in the past, one investigator recalled, "We had been hearing from our communities, you know, that a person shows up, they wanna do research [and] work with them to do a grant, and then they disappear... That was something that made people hesitant to participate..." The SC CPCRN team put time and energy into "... building communities from the inside out" after understanding the viewpoints of the communities. This work involved developing real connections with the people, being trustworthy, and demonstrating genuine authenticity.

Acknowledging the community as experts was another outcome of this committed engagement. The SC CPCRN team was able to meaningfully include the communities' input by listening to and learning from them through the use of activities like narrative mapping.

Developing work that benefited all partners. The SC CPCRN created cooperative initiatives that met the needs of local communities and shared resources. One example is the Right Choice, Fresh Start farmer's market, which started out as a community-led, grantsupported project in 2009 and developed into a successful state program that altered behavior and sparked changes in local and state laws. Further, the SC CPCRN's engagement with communities led to the creation of the Community Health Improvement Program (CHIP) mini grant initiative. Communities can use this mini

grant to obtain SC CPCRN funding to create programs that address local needs. The South Carolina Alliance of YMCAs and the South Carolina Witness Project (SCWP) are the most recent recipients of the CHIP mini grant. The South Carolina Alliance of YMCAs hopes to improve activity rates among South Carolina cancer survivors and boost participation in its 12-week group-based cancer fitness program with the grant funding received. The SCWP aims to address the inequalities that African American and rural women experience in the outcomes of breast and cervical cancer as well as obesity-related comorbidities. Since many of these impacted women don't have access to high-quality healthcare, SCWP hopes that the grant funds will help them increase the number of African American and rural women who get breast and cervical cancer screenings. In addition, they offer guidance and instruction to other health-related services. In an interviewee's words, "... What happens when you really do give folks money and get out of the way? It's magical to watch when you have a system set up to invest in people, build capacity, and just get out of the way. And what community partners did [was amazing]."

Creating an atmosphere of cooperation from research to dissemination. The SC CPCRN creates this atmosphere by working with community partners, which strengthens their dedication for mutual benefit. This involves including community partners as co-authors, fellow researchers, and important contributors to their research and initiatives. In addition, the SC CPCRN works closely with many partners to make sure that their work—which includes taking part in celebrations, developing toolkits for community usage, and making documentaries—can reach and be understood by the communities who participate.

Conclusion:

Overall, this study found key themes from past and present investigators that have made the SC CPCRN's work with community partners successful. Gaining and maintaining the trust of the communities, as well as recognizing their role as experts, has been essential to the SC CPCRN's work and continues to improve its ability to support South Carolina's cancer patients and cancer-related health disparities.

Dr. John Ureda, who died on the 8th of November 2023, was a long-term collaborator and friend to the communities we are all here to serve and whose partnerships are described in this paper. Dr. Ureda brought a strong ethical commitment to his life's work in addressing cancer-related health disparities. His focus on social determinants of disease was on the vanguard of a movement that has changed the face of public health. Because of this, John was greatly beloved by members of the community. Dr. John Ureda was instrumental in imbuing the spirit, philosophy, and methods of community-based participatory research (CBPR) into the work that is reflected in this paper. - as written by Dr. James Hébert

For access to the full manuscript, please contact Dr. Swann Adams, Adams, ADAMSS@mailbox.sc.edu.

Information regarding the CHIP mini grants and current CHIP awardees can be found here.

You can find more information about the SC CPCRN, projects, and their community partners at the <u>SC CPCRN site</u>.

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