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## Community Health Workers Support Community-based Participatory Research Ethics::

### Lessons Learned along the Research-to-Practice-to-Community Continuum

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### Abstract

Ethical principles of community-based participatory research (CBPR)— specifically, community engagement, mutual learning, action-reflection, and commitment to sustainability—stem from the work of Kurt Lewin and Paulo Freire. These are particularly relevant in cancer disparities research because vulnerable populations are often construed to be powerless, supposedly benefiting from programs over which they have no control. The long history of exploiting minority individuals and communities for research purposes (the U.S. Public Health Service Tuskegee Syphilis Study being the most notorious) has left a legacy of mistrust of research and researchers. The purpose of this article is to examine experiences and lessons learned from community health workers (CHWs) in the 10-year translation of an educational intervention in the research-to-practice-to-community continuum. We conclude that the central role played by CHWs enabled the community to gain some degree of control over the intervention and its delivery, thus operationalizing the ethical principles of CBPR.

### Keywords

Colorectal cancer; African Americans; cancer disparities; community-based participatory research; ethics; translational research; community health workers

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Colorectal cancer (CRC) is the second-leading cause of cancer-related death in the United States.<sup>1</sup> The American Cancer Society estimates that some 143,460 people will be diagnosed with CRC in 2012 and approximately 51,690 will die from this disease.<sup>1</sup> African Americans are nearly 50% more likely than Whites to die from CRC. Despite evidence that detection through screening decreases CRC deaths, only about 60% of adults over 50 years of age are adherent to recommended CRC screening guidelines, and the percentage is lower for African Americans.<sup>2</sup> Research suggests that even in the case of interventions proven efficacious, it takes 17 years, on average, for 14% of original research findings to be included in public health practice.<sup>3</sup> If this is the natural course of research translation, it may be difficult to affect CRC screening disparities among African Americans, even when effective interventions exist.

## Community health workers in community-based participatory research

Green and Mercer<sup>4</sup> defined *community-based participatory research* (CBPR) as “a systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting change.”<sup>4</sup>[p.1957] Community-based participatory research could reduce colorectal cancer screening disparities by emphasizing partnerships between investigators and community members in planning, implementation, evaluation, and dissemination of research findings. Theoretically, application of such an approach increases the likelihood that research findings will be readily implemented in communities because communities are invested in the research process.<sup>5</sup>

Community-based participatory research can be viewed as resting on two pillars: ethics and community empowerment.<sup>6</sup> The former is a pillar because meaningful community participation in the research process will help protect communities from exploitation and unethical behavior on the part of researchers. The latter is a pillar because CBPR can offer a transfer of power from institutions that historically hold it (academia and public agencies) to those who have been denied it (low-income and minority communities). In this paper we hope to demonstrate how community health workers have contributed to the ethical pillar, but will refer to their contribution to the empowerment pillar as well.

The ethical pillar of CBPR encompasses the fundamental ethical principles of autonomy, justice, and beneficence.<sup>7</sup> These principles frame an obligation to protect communities as well as individuals from harm. Community-based research violates the principle of autonomy and may violate the others if it is conducted without active community input. Community health workers (CHWs)—also known as community health advisors, natural helpers, and frontline workers—can help provide that input, although they should not bear sole responsibility for carrying out this function.

The World Health Organization (WHO) defines community health workers as individuals who *should be members of the communities where they work, should be selected by the communities, should be answerable to the communities for their activities, should be supported by the health system but not necessarily a part of its organization, and have shorter training than professional workers.*<sup>8</sup>

In conducting CBPR, an important issue is identifying authentic and legitimate community representatives.<sup>6</sup> The WHO definition makes it clear that CHWs serving in a CBPR project may be among those most qualified to represent the views of the community on important health issues and are well-positioned to recognize lapses in research ethics if and when they occur.

Community health workers are now widely used in both research and public health practice involving minority groups.<sup>9–11</sup> Inclusion of CHWs in these programs offers several benefits. For community members, it represents an employment opportunity and a chance to develop useful skills. For investigators, deploying CHWs enhances access to targeted populations and promotes research participation. For research participants, CHWs represent cultural competence in explaining the project and obtaining meaningful informed consent.<sup>12</sup> Finally, for communities, CHWs represent increased capacity for community development.

Community health educators (CHEs) also play an important role in CBPR as well as public health practice. For the purposes of this project, we identified agency (e.g., public health department) representatives and research staff with graduate degrees in a health profession (e.g., health professionals) as CHEs and community members not previously trained as health professionals as CHWs. Community health educators often serve in a role similar to that of CHWs but may not be members of the community in which they serve, have received

most of their training in school rather than on the job, and tend to be regarded by the community as well as by peers as belonging to a different class of health worker.

Several commentators have developed sets of principles to guide CBPR. They include Israel et al. (nine principles),<sup>13</sup> Green et al. (a 23-item checklist),<sup>14</sup> Viswanathan et al. for the Agency for Healthcare Research and Quality (11 “critical elements”),<sup>15</sup> and others.<sup>16,17</sup> In the present analysis, we consider four principles that are particularly relevant to ethical considerations: *community engagement*, *mutual learning*, *action-reflection*, and *commitment to sustainability*.

## CHWs Promoting Ethical Research: A Case Study

This paper describes how CHWs were deployed at each phase of a 10-year CBPR process and how their deployment supported the ethical conduct of research in the community. We begin by describing a randomized controlled trial aimed at determining the efficacy of three approaches to increasing colorectal cancer screening among African Americans. This is followed by a description of local and statewide efforts to demonstrate the effectiveness of the small group intervention, the most efficacious of the three approaches, in public health practice. Finally, we outline our experience of working with 20 community coalitions from across the country to sustain and expand our effort nationally. We then consider the CBPR principles mentioned earlier (*community engagement*, *mutual learning*, *action-reflection*, and *commitment to sustainability*) as they relate to the activities of CHWs. We conclude with a summary of lessons learned in promoting the ethical conduct of CBPR through CHWs.

## Methods

- **Community intervention trial.** From 2002–08, we conducted a randomized controlled community intervention trial—the Colorectal Cancer Screening Intervention Trial (CCSIT)—using a CBPR approach with CHWs. A community needs assessment commissioned by residents of a low-income community identified the need to increase cancer screening as a priority. African American men and women (aged 50 years and older) in the Atlanta GA metropolitan area were randomized to participate in one of three interventions<sup>18</sup> chosen to address evidence gaps in the Guide to Community Preventive Services:<sup>19</sup> one-on-one education, group education, and reducing out-of-pocket costs. A fourth cohort served as a control group. The group education model was the most efficacious of the three; by six months following the intervention, those who participated in it had been screened at twice the rate of those in the control group. Three salaried CHWs played a central role in the project; they recruited participants, administered questionnaires, described the project to community gatherings, helped to deliver the group education intervention, and conducted follow-up with participants.
- **Local practice demonstration.** In 2009–10, we put into practice the group education intervention, now named the *Educational Program to Increase Colorectal Cancer Screening*, or EPICS, in the county’s 15 senior citizen centers. It proved to be as effective in practice as it had been in the research project.<sup>20</sup> Community health workers were key members of the intervention team, helping to deliver the intervention and following up with participants.
- **State practice demonstration.** Based on initial success in public health practice, we initiated a statewide EPICS dissemination and implementation project beginning in 2010. We trained CHW *facilitators* throughout the state of Georgia to

deliver the intervention. These CHWs were volunteers recruited by five of the state's publicly-funded cancer coalitions.

- **National dissemination and implementation.** Starting in 2012, we are partnering with the National Black Leadership Initiative on Cancer (NBLIC) to conduct a national dissemination and implementation trial of EPICS, testing several different conditions under which the intervention will be delivered. The NBLIC is a national network of volunteer coalitions of agency and nonprofit representatives, health professionals, advocates, and cancer survivors focused on cancer prevention and control. Again, this plan will depend on trained volunteer community health workers recruited by NBLIC coalitions at 20 locations in the U.S.

### Finding ideal community health workers

In recruiting CHWs, whether paid or volunteer, we sought individuals with the following characteristics: non-health care professionals with a passion for improving community health and the verbal communication skills to effectively present colorectal cancer information in a culturally appropriate way to persons of diverse educational levels. Community health workers were trained to facilitate EPICS small group sessions; conduct participant follow-up; and implement quality assurance measures. They were trained in a 1½-day highly participatory workshop that was based on principles of Adult Learning Theory.<sup>21</sup> In addition to building the skills needed to conduct the intervention, the workshop emphasized research ethics as applied at the community level.

## Results

Table 1 presents demographic characteristics of CHWs and community health educators. A total of 100 individuals, primarily African American (71%) and female (77%) participated in this effort. Community health workers, representing targeted communities, constituted nearly 50% of the staff in the translational process.

Community health workers were key members of the intervention team in each of the four projects, contributing to facilitator training modules, implementation protocols, educational materials and development of a plan to promote sustainability (Figure 1). Community health workers led the way in participant recruitment and retention. Regarding the four ethical principles cited earlier, the CHWs contributed the following:

### Community engagement

The CHWs helped engage the academic team with the community and reflected community input to facilitate the project. For instance, they recommended additions to the EPICS toolkit, such as brochures, to increase the acceptability of the intervention. Three facilitator training modules were developed in collaboration with CHWs during the state practice demonstration. A male CHW was hired specifically to recruit men to the initial trial.

### Mutual learning

While university-based researchers practicing CBPR are willing to cede some power and resources to the community, they may be reluctant to admit that they can learn something from the community. This elitism violates the ethical notion that the community is actually the senior partner and that mutual learning can take place. Once elitist attitudes are overcome, researchers must find people to help them, people who can function as teachers who can not only convey information from them to the community, but also can also transfer information and wisdom to them *from* the community. Community health workers can play this role, and in our projects they often did, sharing with academic researchers

insights on community attitudes relevant to participant recruitment and retention in the project. It was, for instance, the project's CHWs who explained to the academic team that an intervention that required four sessions—the original EPICS model—would not retain participants. At the same time, the academics relied on the CHWs to explain to health department professionals that EPICS could not be reduced to a single long session, since the social interaction of the group over multiple sessions was an essential element of the intervention. As a result of this negotiation, the intervention was reduced from four to three sessions, with no loss of effectiveness.

### Action-reflection

As one adapts a proven health promotion intervention for varying audiences, it is essential to retain core elements. This is an ethical issue: with the core elements retained, the intervention is evidence-based, and implementing it represents public health practice, not research. On the other hand, if the adaptation alters the core elements, the intervention is no longer evidence-based. It is a new, experimental intervention, and implementing it is a research initiative, subject to all the ethical protections of human subjects that attend any research project. Determining the core elements requires action, reflection, and modification. *Action* in our program was represented by the development and implementation of the intervention in communities. As the communities included both urban and rural sites within Georgia and varying settings in several different states, several different adaptations of the intervention were needed. It was the CHWs who *reflected* as members of the intervention team on the approaches that could be taken while retaining the core elements at each site. The reflection process with the CHWs provided us the opportunity to discuss the core elements that must be *adopted*, while pointing out those non-core elements that could be *adapted*.

### Commitment to sustainability

Sustainability is an important ethical element in CBPR. University researchers have historically earned reputations as exploiters by walking away from their community partners when their three-year grant expires. In our program, the CHWs, as representatives of their communities as well as implementers of the intervention, had the most to lose if the program were not sustained. For those CHWs who were paid employees of the project, they could lose their jobs. Whether paid or not, their communities would suffer if the program were to disappear. They therefore were eager to work with us to help develop grant proposals and other approaches to sustain the initiative.

Factors promoting the achievement of each of these principles, and the role of CHWs, are summarized in Box 1.

### Discussion

Five lessons were learned as we engaged in the participatory process with communities across the country. These lessons included: 1) ethical considerations should undergird all activities; 2) community commitment to the project is a must; 3) CHWs must be empowered to bridge the research-to-practice gap; 4) training is fundamental; and 5) technical assistance is required.

1. **Ethical considerations should undergird all activities.** Scientific rigor and the mechanics of intervention delivery are important but they can never be allowed to override the ethical imperatives associated with conducting research in the community. Avoidance of exploitation must guide all actions: academicians should not benefit at the expense of the community. Power must be transferred to the community; it is unethical to claim an academic-community partnership if all

power and control is vested in the academic partner. Resources must also be transferred to the community; it is unethical to claim an academic-community partnership if all the resources remain at the academic institution. CHWs are important participants in carrying out this mandate. Empowering them to define how and where the intervention is to be delivered, to adapt the intervention protocol (without altering the core elements), and to serve as the bridge between the academic institution and the community helps operationalize the power-sharing principle. Paying them a decent salary is one way in which to share resources with the community (although volunteer CHWs are prominent both in our program and in many others). At the same time, it must be recognized that salaried CHWs may find themselves caught in a conflict of interest: if they are paid employees of the academic institution, they may find it difficult to serve the community's interest if they find their employer engaged in exploitative behavior.

2. **Community commitment to the project is a must.** This is a corollary of the *community engagement*, *action-reflection*, and *mutual learning* principles. Like politics, community engagement is local. There are a variety of ways of identifying community needs—focus groups, surveys, morbidity and mortality data. However, these approaches are static; they offer only a snapshot of community priorities at a point in time. By including locally-recruited CHWs as members of our team, we were able learn how to adapt the intervention and thus promote community commitment to the project and trust in the academic partners.
3. **Community health workers must be empowered to bridge the research-to-practice gap.** Ultimately, this represents the principle of *commitment to sustainability*. Academic institutions have developed elaborate infrastructures to support research and medical care delivery, but little or none to support public health practice. Hence, to translate our research findings into practice we had to form partnerships. Our initial partnership was with the local health department, and the CHWs represented the bridge between our academic institution and the health department. Moreover, the CHWs were essential in sustaining our relationship with the community. In order to carry out these functions, the CHWs had to be more than deliverers of an intervention designed by academics; they had to have the power to modify the intervention. Hence, an important component of transferring power from the academic institution to the community is to place some of that power in the hands of the CHWs. It was through these bridging and empowerment functions that the colorectal cancer screening intervention became institutionalized and sustained.
4. **Training is fundamental.** This is another manifestation of the *mutual learning* principle. Underlying the empowerment of the CHWs is training so that they understand not only the mechanics of delivering the intervention but also the principles and theory upon which it is based. Our training for the local practice demonstration included two health educators and four CHWs. At the same time, based on input from CHW facilitators, we learned the importance of expanding training to meet the needs of all CHWs.
5. **Technical assistance is required.** This is an expression of the *community engagement* and *action-reflection* principles. Initially, it was not clear whether it was necessary to offer technical assistance (TA) and, if so, at what point it was needed. However, we soon realized that one of the benefits of TA was enhanced capacity building in communities participating in EPICS demonstrations. In other words, one part of transferring power to the community is the requirement that it be



transferred on an ongoing basis. Continuing training can be provided to the CHWs and they, in turn, can be the agents of TA and community capacity building.

Initial TA needs were identified informally when requests were made of the academic team. In addition to the CHWs, the requests were relayed to community leaders and partnering agency representatives. The confluence of experiences (action) and thought (reflection) combined to create the technical assistance content which transformed the dissemination and implementation process. Reflection was used as the vehicle for critical analysis, problem-solving, synthesis of opposing ideas, evaluation, identifying patterns and creating new approaches to intervention delivery. These TA requests were related to understanding colorectal cancer screening, intervention delivery skills enhancement, completing quality assurance measures, effective communication with partners, and community engagement. Further understanding of the role of TA in successful dissemination of the intervention is one of the foci of the newest of the EPICS initiatives.

## Conclusion

Community health workers are often viewed as little more than a project's least-skilled field staff. But in community-based participatory research they are much more. They can secure community commitment to the project. They can make it possible to bridge the research-to-practice gap. Most importantly, they can bolster the two pillars of CBPR: community empowerment and ethics. With regard to the first, they can play a key role in enabling the community to build capacity and gain control of resources. Respecting the second, they can ensure that the project adheres to the principles of research ethics in the community.

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## Notes

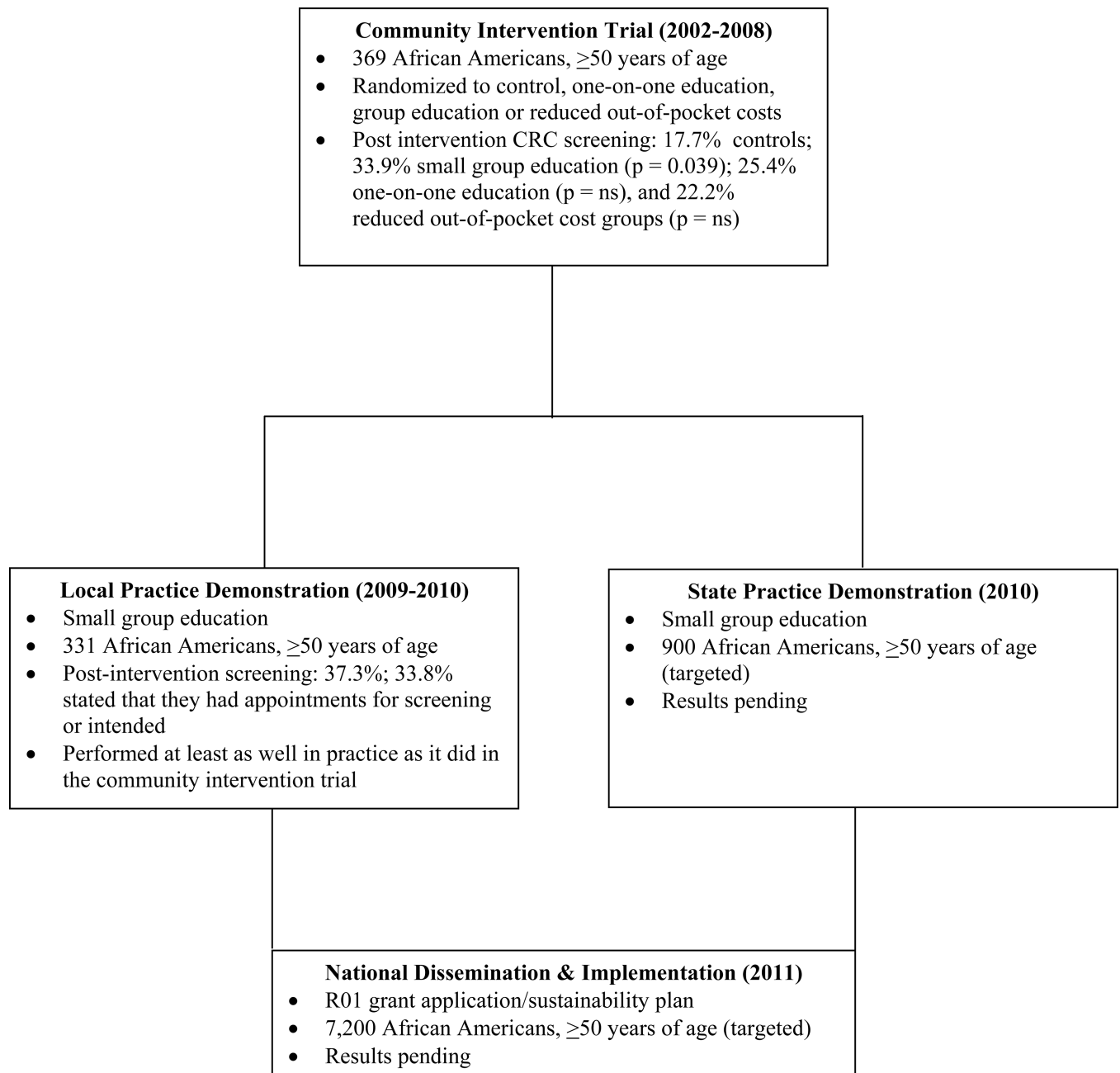
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**Boxed Text**

Key CHW Contributions to a 10-Year Research-to-Practice-to-Community Translational Process



**Figure 1.** Educational program to increase colorectal cancer screening: research-to-practice-to-community continuum.

**Table 1**

Community Representative Characteristics by Translational Process Phase

Characteristic	Community intervention trial	Local practice demonstration	State practice demonstration	National dissemination & implementation	Total
<b>Racial Ethnic Group</b>					
African American	4	6	35	30	75
White			19		19
Hispanic/Latino			4		4
Asian/Pacific Islander			2		2
<b>Gender</b>					
Male	1	3	7	7	18
Female	3	3	53	23	82
<b>Education</b>					
High School		4	30	13	47
College/Grad School	4	2	30	17	53
<b>Profession</b>					
Health Educator	3	2	30	17	52
Community Health Worker	1	4	30	13	48
<b>TOTAL</b>	4	6	60	30	100