

Participatory Process for Implementing a Colorectal Cancer Screening Intervention: an Action Plan for Local Sustainability

Selina A. Smith, PhD, MDiv¹, Joyce Q. Sheats, RN, MPH¹, Sandra J. Hamilton, RN, MEd², Mary S. Whitehead, MPH, CHES³, Ernestine P. Delmoo, MPH⁴, Thomas Britt, MD, MPH⁵, Cassandra L. Harris, MS, MCHES⁶, Janette Robinson-Flint⁷, Cheryl A. Johnson, MPAH⁸, Corliss McKeever, MSW⁹, Connie L. Sorrell, MPH¹⁰, Vincent R. Green¹¹, John W. Harmon¹², Dorothy L. Reddic, MEd¹³, Jane Giddens-Cabarrus¹⁴, Shirley Jordan-Seay, PhD, OCN, CTR¹⁵, Benjamin E. Ansa, MD, MSCR¹⁶, and Daniel S. Blumenthal, MD, MPH¹⁷

¹Department of Family Medicine, Medical College of Georgia, Augusta University, Augusta, GA; ²National Black Leadership Initiative on Cancer, Memphis Coalition, Memphis, TN; ³Florida Resources for Enhancing and Sustaining Health, Miami, FL; ⁴National Black Leadership Initiative on Cancer, Philadelphia Chapter, Philadelphia, PA; ⁵National Black Leadership Initiative on Cancer, Chicago Coalition, Chicago, IL; ⁶National Black Leadership Initiative on Cancer, Houston Coalition, Houston, TX; ⁷Black Women for Wellness, Los Angeles, CA; ⁸West Central Georgia Cancer Coalition, Columbus, GA; ⁹African American Health Coalition, Inc., Portland, OR; ¹⁰Kentucky African Americans Against Cancer, Louisville, KY; ¹¹Atlanta Cancer Awareness Partnership, Inc., Atlanta, GA; ¹²National Black Leadership Initiative on Cancer, Augusta Coalition, Augusta, GA; ¹³Black Healthcare Initiative Coalition, Rockford, IL; ¹⁴National Black Leadership Initiative on Cancer, Virginia Coalition, Nassawadox, VA; ¹⁵Nu Chi Chapter of Chi Eta Phi Sorority, Inc., Cleveland, OH; ¹⁶Institute of Public and Preventive Health, Augusta University, Augusta, GA; ¹⁷Department of Community Health and Preventive Medicine, Morehouse School of Medicine, Atlanta, GA

Corresponding Author: Benjamin E. Ansa • Institute of Public and Preventive Health, Augusta University, 1120 15th Street, Augusta, GA, 30912 • 706-721-6141 • bansa@augusta.edu

ABSTRACT

Background: Rigid protocols can hamper translation of evidence-based interventions from research to real-world settings. This investigation aimed to develop procedures for modifying the study protocol of a community-based participatory research (CBPR) project and to analyze the theoretical constructs that underlie this process.

Methods: The research project is a dissemination and implementation study of the Educational Program to Increase Colorectal Cancer Screening (EPICS), an evidence-based intervention targeting African Americans in the United States. The study is being conducted in a partnership with community coalitions in 15 different cities. Each site initially presented unique issues that required modification of the study protocol.

Results: In order to honor underlying CBPR theory, it was necessary to negotiate protocol changes with the community coalition at each site, while insuring preservation of the core elements of the intervention.

Conclusions: We discuss the ways in which this represents a narrowing of the gap between CBPR and traditional research approaches.

Keywords: Community-based participatory research, colorectal cancer screening, evidence-based intervention, implementation and dissemination, sustainability

<https://doi.org/10.20429/jgpha.2019.070202>

INTRODUCTION

Community-based participatory research (CBPR) is an approach in which research scientists partner with a community to develop, conduct, and analyze a research project and disseminate its results. Ideally, the research protocol is created jointly by the investigators and a community advisory board, a community coalition, or the equivalent; at a minimum, community representatives review a protocol developed by the investigators and approve it after negotiating changes that reflect community values, priorities, and/or preferences (Community-Campus Partnerships for

Health; Green et al., 2003; International Collaboration for Participatory Health Research (ICPHR). 2013; Israel et al., 1998). In many respects, community coalitions, comprised of a diverse group of members committed to effecting change, undergird CBPR (Smith et al., 2015; Kluhsman et al., 2006; Raine et al., 2013; Cromley et al., 2011).

In this paper, we describe a CBPR dissemination and implementation research project whose aim is to determine the most efficacious approach to the dissemination of an intervention to promote colorectal cancer screening among African Americans (Educational Program to Increase

Colorectal Cancer Screening, “EPICS”) and to identify factors associated with its effectiveness.

When a single project involves several communities, each with its own coalition, CBPR takes on new dimensions. The EPICS project involves 15 communities in as many cities; in this paper, we discuss our approach to modifying the research protocol to address the concerns of our partner coalitions in each location. Two brief case studies from Augusta, GA, and Philadelphia, PA, were described to help illustrate most of the challenges identified by the coalitions. We note the ways in which we were able to retain the core elements of the study without violating the trust of our partners.

BACKGROUND

The disparity

Colorectal cancer (CRC) is the second leading cause of cancer-related deaths in the United States and the third most common cancer in men and in women (U.S. Cancer Statistics Working Group (USCSWG). 2017). Relative to other racial or ethnic groups, African Americans (AAs) have the highest over-all incidence, the highest incidence of advanced stage at disease presentation, the highest attributable mortality, and the lowest survival rates after diagnosis (Howlader et al., 2017). In 2016, an estimated 17,240 cases of CRC and 7030 deaths from CRC were expected to occur among AAs. The mortality rate in men is 27% higher in blacks than in whites; in women, the mortality rate is 22% higher in blacks. Racial disparities in CRC death rates may be explained by differences in the use, availability, and quality of screening and treatment services (American Cancer Society, 2016).

Screening can prevent deaths by detecting CRC in an early, more treatable stage and by detecting and removing its nonmalignant precursor lesions. Lansdorp-Vogelaar et al (2012) reported that differences in CRC screening accounted for 42% of disparity in CRC incidence and 19% of disparity in CRC mortality between Blacks and Whites. Among AAs, substantial differences exist between individuals who are adherent to screening guidelines and those who have not undergone screening (Lansdorp-Vogelaar et al., 2011). Adherent individuals are more knowledgeable about CRC and hold positive beliefs about the benefits of screening, but non-adherent individuals place little importance on prevention and early detection (Lansdorp-Vogelaar et al., 2011). Physician recommendation and insurance coverage/cost also differentiates the two groups (Lansdorp-Vogelaar et al., 2011). Culturally- specific interventions are needed to address CRC screening disparities among AAs (See Appendix 1).

The intervention

The Educational Program to Increase Colorectal Cancer Screening (EPICS), which has been described elsewhere (Blumenthal et al. 2010; Smith et al., 2012) is an effective intervention for increasing CRC screening rates among AAs in both a research setting and in practice. Briefly, age-eligible AA men and women who have not been screened for CRC within the recommended time interval are recruited to

participate in three small-group (8-12) educational sessions conducted by a facilitator who is a professional community health educator or a trained lay community health worker. The eligibility criteria for this project were: being African American, aged >49 years, no history of CRC, and no previous CRC screening test within the recommended time interval. Two full-time and one part-time facilitator made contacts in person at senior centers, churches, community centers, and public health clinics. The sessions, conducted a week apart, include information and discussions on CRC, on primary prevention and screening, and on cancer more generally. A follow-up to determine whether participants have been screened is conducted three months later.

The dissemination and implementation trial

The dissemination and implementation trial is conducted in partnership with 15 community coalitions that were organized by the National Black Leadership Initiative on Cancer (NBLIC) in cities across the United States. NBLIC is a program that was launched in 1985 by AA businessmen, academics, and cancer survivors and advocates (Satcher et al., 2006). From 1989 until 2010, a central coordinating office was funded by the National Cancer Institute (NCI). While this office no longer exists, most of the community coalitions continue and focus on cancer prevention education and advocacy among AAs. The coalitions are not homogeneous across sites; some are comprised primarily of health professionals; others are primarily cancer survivors and advocates; some have relatively equal numbers of the two. Some are funded by grants or donations; others function only through the work of volunteers. Each of the coalitions participating in the current project receives a small grant to support its efforts.

The specific aims of the dissemination and implementation trial are to determine the most efficacious approach to the dissemination of EPICS and to identify factors associated with its effectiveness. A computer program generating random numbers between 1 and n was used to assign 15 NBLIC community coalitions to one of four conditions:

1. Website access to facilitator training materials and toolkits without technical assistance (TA). The materials and toolkits are posted on the NCI website in the Research Tested Intervention Programs (RTIPs) section (Colorectal Cancer Screening Intervention Program-RTIPs).
2. Website access with TA; materials are accessed from the RTIPs website, and, in addition, the investigators offer in-person TA.
3. In-person access to facilitator training materials and toolkits without TA;
4. In-person access to facilitator training materials and toolkits with TA.

Fidelity to the core elements of intervention delivery is evaluated by recurrent site visits by one of the investigators. Follow-up is conducted by the facilitators. TA is any kind of assistance or response (that is not administrative) given to the coalition leaders to effectively implement the protocol. An example of TA is responding to questions on how to reach

study participants for the 90 day follow-up if their contact addresses have changed.

EPICS investigators include an interdisciplinary team of seven researchers with expertise in health disparities, cancer control, CBPR, biostatistics, and health economics. Located at two medical schools in Georgia, EPICS investigators work closely with NBLIC leaders to disseminate research results (i.e., peer-reviewed publications, scientific conferences, local newspapers) and expand CBPR opportunities (i.e., grant funding). Members of the investigative team have partnered with NBLIC since its inception, including 16-years of experience through three funded studies researching CRC screening in AA communities.

Core elements

In adapting the project to recognize local conditions and preferences, the core elements of the project must be preserved. The core elements of the intervention are displayed in Table 1, along with options for adapting them. They include:

- **Theoretical framework (intervention):** The intervention is based on Social Ecological Theory (Breslow, 1996) and Social Cognitive Theory (Bandura, 1986). These theories suggest that the informational and emotional support received by participants in a support network may encourage participation in cancer screening despite possible psychological barriers. The involvement of family members, friends, volunteers, and others are important (Lee, 2004). These theories are fundamental to the intervention; there is no adaptation option for them.
- **Theoretical framework (Dissemination/Intervention trial):** The present project is a trial of four dissemination modalities: facilitated via the Worldwide Web with and without technical assistance, and in-person training with and without technical assistance. The trial is based on the Dissemination of Innovation theory (Rogers, 2003). Three components of this theory are key:

- **Communication.** The most effective communication strategy is face-to-face exchange.
- **Collaboration.** The relationship between developers (researchers), change agents (NBLIC community coalitions) and early adopters (community members) is important to successful dissemination.
- **Environment.** A supportive environment is essential in promoting intervention uptake. There is no option for altering the project's four independent variables; for instance, a site designated for in-person training could not also be given access to web-based training.
- **Educational content of intervention:** The intervention offers fundamental information about colorectal cancer and screening guidelines. While the information is factual and therefore cannot be modified, the details of presentation could be adapted – for instance, to fit the educational and literacy level of participants. The intervention also includes information about diet and physical activity relevant to cancer prevention generally; there is room to adapt this information to participant background.
- **Intervention Sessions:** The intervention is based on group discussion and the development of supportive interaction among participants, as called for by the theoretical framework. Hence, the size of the group could be adjusted, but there must be a group (as opposed to individual educational sessions). Similarly, there could be more than three sessions, but three is probably the minimum necessary to generate the desirable level of interaction.
- **Intervention facilitators:** In the original study, the intervention was conducted by a health educator together with trained lay community health workers. However, with appropriate training, others (ranging from nurses to cancer survivors) could serve in the same roles; the laypersons would, in a sense, become community health workers.
- **Settings:** The intervention was originally delivered in clinics, churches, and community centers. However, almost any facility could be used.

Table 1. EPICS Core Elements

Element	Basic Approach	Adaptation Option
Theoretical Framework (intervention)	Social Ecological Theory; Social Cognitive Theory	None
Theoretical Framework (Dissemination/Implementation Trial)	Dissemination of Innovation Theory	None
Dissemination Modalities	Website access to training with and without TA; In-person access to training with and without TA	None
Educational Content of Intervention	Guidelines for CRC (DRE; FOBT, Sigmoidoscopy; Colonoscopy); CRC Risk Factors *	Dietary and physical activity information adapted to fit the audience
Intervention Sessions	Group settings; three (3) one-hour sessions	Size of groups may be increased (≤ 20); total number of sessions may be increased to 4
Intervention Facilitators	Health educators and trained lay community health workers	Public health professionals, cancer survivors, cancer advocates, community members, church and civic leaders
Facilitator Training	1 ½ day in-person training; web-based training is on NCI website. TA is flexible, based on individual coalition needs.	In-person training longer, or spread over more days, according to facilitator needs. Web-based training is fixed, not adaptable.
Settings	Churches, clinics and community centers	Other settings
*DRE, digital rectal examination; FOBT, fecal occult blood test; TA, technical assistance		

METHODS

The Institutional Review Board (IRB) of Augusta University approved the research plan. Informed consent was obtained for all study participants: community coalition leaders, facilitators, and individual participants. From April-September 2015, EPICS investigators led four-hour, in-person guided discussions with leaders of each of the 15 NBLIC community coalitions. The purposes of this interactive process were to share information and experiences related to EPICS implementation and to develop action plans for enhancing its dissemination. Results-to-date, which outlined settings for delivery, numbers of participants reached, and characteristics of facilitators leading EPICS sessions, were presented. Participants then engaged in a SWOT (strengths, weaknesses, opportunities, threats) analysis to define implementation challenges. Strengths were defined characteristics of community coalitions needed to deliver the evidence-based intervention, weaknesses as challenges or barriers to implementation, opportunities as elements that could be exploited, and threats as contextual risks to successful completion of the study.

Specific, measurable, achievable, realistic, and timely (SMART) goals related to facilitator and participant recruitment and retention were established, with modifications needed in the study protocol to reach these goals. These modifications were summarized in an action plan. Following each discussion, a draft action plan was distributed to community coalition leaders, who shared it with other coalition members, revised it, and submitted it to

EPICS investigators for review. The final action plan was distributed to all community coalition members. The coalition reviews were guided by a set of NBLIC principles that had been developed in partnership with researchers and resonated well in the AA community. These principles are not an algorithm or recipe for conducting community-based research, but emphasize trust, solidarity, and a participatory approach. They help define the approach that researchers and community partners take in designing and implementing research projects. The principles are attached to this article as an appendix.

Information from the guided discussions is summarized in Table 2, listed by study site. The main barriers to EPICS implementation, as identified by community coalition

members are listed and are sorted by theme. The major themes include: 1) facilitator recruitment, training and roles and 2) participant recruitment and retention. The table then lists the elements of the action plans. Although the two general themes describe most of the challenges identified by the coalitions, the specifics were unique to each site, and each action plan was thus different. Two brief case studies help to illustrate:

Augusta GA: Augusta is a city of around 200,000 population located about 150 miles from Atlanta. It is the site of Augusta University, which includes a major medical center comprising colleges of medicine, nursing, allied health sciences, and dentistry and a university hospital. Hence, a considerably greater number of health professionals live in Augusta than would usually be found in a city of its size. This impacts the community coalition, which is largely made up of health professionals with a particular interest in cancer. Hence, it was not difficult for the Augusta coalition to recruit some of its members as facilitators, and most of the facilitators were well-educated health professionals. At first glance, it might seem that this would benefit the project, but in reality, the reverse was true. First, many facilitators did not engage well, often shortening sessions or missing them entirely. They may have been a result of the facilitators' orientation to very sick patients rather than well individuals in a prevention project. Secondly, the facilitators' ideas of the best approach to conducting sessions, the information that needed to be communicated, and the language to be used in communicating this information often differed from the protocol and did not reflect fidelity to the core elements of the intervention. This led to a series of meetings with the coalition to attempt to resolve these issues. Since the meetings were not recorded, it is not possible to offer extensive verbatim quotes in this report.

CBPR principles make it clear that the community partner – the coalition – is the “senior partner” in the collaboration with the university. But the subtext to this principle is the question of “who represents the community?” (Blumenthal, 2006). In the case of the EPICS project in Augusta, the relevant community was the city's African-American citizenry, particularly those over the age of 50 (for whom colorectal cancer screening is recommended). While the members of the coalition were African American, as healthcare professionals they imperfectly represented the community.

Hence, the discussion between the university representative and the coalition was initially difficult, since some of the coalition members pointed out that they had received training in health education, knew about colorectal cancer, and understood very well the importance of screening.

To counter the pushback, the university representative pointed out the high dropout rate among study participants and asked the coalition members to suggest approaches to remedy this problem. Two such approaches emerged from the discussion. The first was the suggestion of a coalition member: incentives (such as gift cards) to be distributed to participants at the end of each session to promote retention in

the project. The second – additional facilitator training – was the product of conversation between the university representative and coalition members, with the elements of the training suggested by both parties.

The additional training included both new facilitators and the original cohort. The focus of the coalition was on the practical steps needed to advance the project, while the focus of the investigators was on the core elements of the intervention and adhering to the protocol to the extent possible. Neither of these strategies (incentives, additional training) was called for in the protocol but we found them to be necessary. Ultimately, the health professions backgrounds of the facilitators proved salubrious, as they did understand the importance of following guidelines even if they intuitively thought that some other approach would be superior. As one facilitator remarked (and can be recalled), “I originally thought that my background as a nurse was all I needed to do this project, but in the end I understood that this was research and that there was a protocol that had to be followed.”

Philadelphia PA: Philadelphia differs from Augusta in that it is a metropolis of over 1.5 million people. It has five medical schools (including the osteopathic school) but with a much larger population than Augusta, its coalition is drawn from more diverse sectors and includes more business people, cancer survivors, and patient advocates than does the Augusta coalition. While there are many strengths in a diverse coalition, laypeople are often fearful of taking on roles that they see as the province of health professionals. Hence, the coalition encountered difficulties in recruiting facilitators from its membership. Too few facilitators resulted in too few intervention participants, since one of the facilitators' roles was recruiting participants.

We developed our response to this issue after conferring with the Philadelphia coalition. Again, the meetings were not recorded.

As in the case of the Augusta coalition, it was important to recognize the community coalition as the “senior partner” whose perspectives took precedence in discussions with university representatives. Coalition members emphasized that they did not see themselves as health educators but rather as concerned citizens whose role it was to encourage the health professionals to act on health disparities but not to serve in health worker roles themselves. In addition, many coalition members had full-time jobs and were not available to serve as volunteer community health educators.

A solution that arose from the suggestions of coalition members was to reach out to other organizations in the Philadelphia area, such as sororities and civic groups, organizations whose members often served in volunteer service roles. The new facilitators, in turn, served as role models for the original facilitators, demonstrating that lay people could do this work well. The new facilitators had to be trained, and the original facilitators were included in the training, both to increase their skills and their confidence.

Table 2. Local EPICS Implementation Action Plan

Community-Specific Challenges	Facilitators			Participants	
	Recruitment	Training	Roles	Recruitment	Retention
<p>Augusta, GA</p> <ul style="list-style-type: none"> • Lack of facilitator engagement • Limited diversity in settings • Low levels of participants recruited • Scheduling conflicts with settings • Lack of core element knowledge 	Incentivize facilitator participation.	<p>Train additional facilitators; include existing facilitators in training to review core elements/action plan.</p> <p>Emphasize fidelity to core elements during training.</p> <p>Hold quarterly facilitator review sessions.</p>	<p>Include a communications facilitator to contact participants immediately following a session to thank them for participating and remind them of the next session.</p>	<p>Develop a letter of introduction to provide to settings.</p> <p>Provide nametags for facilitators to wear when recruiting.</p> <p>Develop a list of senior citizen centers; enlist activity coordinators to serve as liaisons; discuss potential scheduling conflicts in advance.</p>	<p>Schedule a pre-session with recruited participants to introduce the program.</p> <p>Schedule make-up sessions for individuals missing a session.</p> <p>Serve refreshments at each session.</p>
<p>Memphis, TN</p> <ul style="list-style-type: none"> • Competing commitments • Lack of data collection coordination • Low adherence to protocols • Limited access to screening • Lack of diversity in settings 	Identify facilitators from surrounding county.	<p>Meet with facilitators monthly and provide educational updates.</p> <p>Provide transportation stipends (based on mileage).</p> <p>Include monitors trained on data collection measures to assist participants in completing surveys.</p>	<p>Include a data collection facilitator to ensure that each survey instrument is checked for completion prior to the end of each session.</p>	<p>Use local transportation service to support participation.</p> <p>Partner with senior centers, housing authority, local community action and team.</p> <p>Advertise on TV and radio and recruit at health fairs.</p>	<p>Offer non-monetary incentives.</p> <p>Attach sessions to existing activities.</p> <p>Provide a resource guide with access to free/reduced cost screening.</p>
<p>Philadelphia, PA</p> <ul style="list-style-type: none"> • Limited participant recruitment 	Train additional facilitators.	Train new facilitators and re-train existing facilitators.	Identify, train and incentivize junior ambassadors to assist.	“Each one, bring one” strategy to involve	Include a pre-session strategy to reduce initial

<ul style="list-style-type: none"> • Lack of participant retention • Length of first session • Limited number of facilitators • Poor data management 		<p>Add presenter, communicator, and data collector facilitators</p>	<p>participants in recruitment.</p> <p>Expand recruitment sources.</p>	<p>session length.</p> <p>Follow-up with participants immediately following each session.</p> <p>Add additional incentives distributed after each session.</p>	
<p>Norfolk, VA</p> <ul style="list-style-type: none"> • Insufficient number of facilitators • Lack of incentives for participation • Lack of creative incentives • Competing commitments • Limited male enrollment 	<p>Provide incentives (e.g., gas card).</p>	<p>Train additional facilitators.</p> <p>Assign facilitators based on session size.</p>	<p>Identify a marketing facilitator.</p> <p>Pair experienced facilitators with new facilitators.</p>	<p>Examine sources for male participants and create opportunities for engagement.</p> <p>Employ different strategies for urban and rural communities.</p> <p>Provide incentives to settings for partnering in implementation.</p>	<p>Develop creative incentives (e.g., travel kit, cookbook, fruit and vegetables) for each session.</p> <p>Connect EPICS sessions to other activities.</p> <p>Include refreshments for each session.</p>
<p>Cleveland, OH</p> <ul style="list-style-type: none"> • Lack of diversity in facilitators • Limited facilitator engagement • Long initial session • Limited enrollment due to weather • Saturation of geographical area 	<p>Provide incentives for training and delivering sessions.</p>	<p>Provide continuing education units for training.</p> <p>Train non-health professionals as facilitators.</p> <p>Recruit nursing students.</p>	<p>Assign role-specific duties to facilitators.</p> <p>Include a data manager facilitator to ensure efficient data collection.</p>	<p>Deliver as many sessions as possible during good weather months.</p> <p>Provide transportation stipends for participants.</p> <p>Expand to surrounding counties.</p>	<p>Conduct a pre-session to reduce Session 1 length.</p> <p>Utilize students to assist participants with low literacy in completing surveys.</p>
<p>Houston, TX</p> <ul style="list-style-type: none"> • Limited participant recruitment • Lack of participant retention 	<p>Recruit additional facilitators.</p>	<p>Review the action plan as a way of re-training existing facilitators.</p>	<p>Identify a facilitator to enhance participant communication.</p>	<p>Include a recruitment session to complete informed consent,</p>	<p>Provide refreshments at each session.</p> <p>Schedule make-up</p>

<ul style="list-style-type: none"> • Lack of diversity in facilitator roles • Early age at diagnosis for AA men 	<p>Conduct monthly training updates.</p>	<p>Utilize volunteers to assist in non-education roles.</p>	<p>eligibility query and baseline questionnaire.</p>	<p>sessions for participants missing a session.</p>	
	<p>Provide periodic TA.</p>		<p>Enhance recruitment settings.</p>	<p>Educate average risk 45 year old AAs.</p>	
<p>Chicago, IL</p> <ul style="list-style-type: none"> • How to include non-AAs • Lack of student opportunities • Limited weather-friendly months for implementation • Low literacy among participants 	<p>Create educational opportunities.</p>	<p>Re-train existing facilitators.</p> <p>Identify creative approach to training</p> <p>Include health profession students (e.g., nurses, health educators) in the training.</p>	<p>Develop facilitator teams.</p> <p>Pair experienced with less-experienced facilitators.</p> <p>Identify volunteers to assist in data collection.</p>	<p>Attach sessions to community events.</p> <p>Connect participant recruitment to existing lifestyle study.</p> <p>Develop neighborhood-specific recruitment strategies.</p>	<p>Explore web-based delivery of small group sessions.</p> <p>Offer screening (e.g., FOBT) opportunities through community agencies (e.g., local health department).</p>
<p>Miami, FL</p> <ul style="list-style-type: none"> • Inefficient approach to data collection • Limited coordination between coalition leadership and facilitators • Lack of facilitators • Limited community partners 	<p>Identify and recruit facilitators available during peak times.</p>	<p>Conduct new facilitator training.</p> <p>Meet with facilitators every two months.</p> <p>Provide incentives for facilitators.</p>	<p>Establish facilitator teams.</p> <p>Include a data collection/submission team and a site location team.</p>	<p>Work closely with potential partners to recruit their constituents as participants.</p> <p>Use the DHHL* cookbook in general and the Miami recipes specifically, to engage community organizations as partners.</p> <p>Utilize existing coalition activities to promote the study.</p>	<p>Provide incentives at the end of each session.</p> <p>Include a special activity (e.g., “Ask the Doctor,” or cooking demo) following each session.</p> <p>Seek donations from companies (e.g., Whole Foods) to donate food (e.g., fresh fruits and vegetables) offered to participants.</p>
<p>Rockford, IL</p> <ul style="list-style-type: none"> • Lack of leadership succession plan 	<p>Cross train facilitators for new roles.</p>	<p>Train and certify current volunteers as</p>	<p>Define roles for facilitators during training.</p>	<p>Include a pre-session to promote the</p>	<p>Conduct make-up sessions for participants.</p>

<ul style="list-style-type: none"> Limited facilities for holding sessions Limited research experience Lack of communication with participants 	facilitators.	Existing facilitators will train new facilitators.	Meet regularly to review protocols and action plan.	study.	Provide a telephone follow-up immediately following each session.
	Communicate changes in implementation protocol.	Expose facilitators to research by discussing methods for other community interventions.	Conduct face-to-face recruitment by presenting an overview of the study to community organizations.	Partner with existing organizations (e.g., housing authority) to enhance recruitment.	
<p>Orlando, FL</p> <ul style="list-style-type: none"> Competing priorities Limited participant incentives Lack of planning Insufficient advertising 	Expand to other Central Florida communities.	Dedicate time to planning sessions with facilitators.	Combine multiple roles for facilitators.	Conduct a pre-session to enhance participant recruitment.	Schedule make-up sessions immediately following missed sessions.
		Train facilitators on modifications to the protocol.	Enhance data collection by assigning the task to one facilitator.	Rely on community connections to identify eligible participants.	Provide incentives during each session.
		Enhance marketing to facilitators.			Strengthen sessions by inviting other cancer-related groups to the final session.
<p>Columbus, GA</p> <ul style="list-style-type: none"> Limited focus on AA audiences. Saturation of the targeted community AA men diagnosed at younger ages. Limited group size. 	Train additional facilitators.	Train new facilitators and re-train existing facilitators.	Communication facilitator is key to sustainability.	Expand catchment area to include communities in neighboring state.	Attach sessions to other community activities.
		Include modifications to the protocol based on the action plan.	Include a Spanish-speaking facilitator to assist as needed.	Recruit younger participants in addition to coalition goal.	Include non-AA participants in sessions.
				Enlist multiple facilitators to educate large groups.	

<p>Los Angeles, CA</p> <ul style="list-style-type: none"> • Limited engagement in sessions. • Lack of fit into existing coalition activities. • Poor data management. • Conducting 3 face-to-face sessions. 	<p>Train additional facilitators.</p>	<p>Cross train facilitators from other programs.</p>	<p>Assign data collection and management to one facilitator.</p> <p>Follow-up with data coordinating center following data submission.</p>	<p>Use existing programs for recruitment (e.g., diabetes).</p> <p>Engage pastors at local churches to add credibility to the study.</p> <p>Communication with participants following sessions.</p>	<p>Include Kitchen Divas (e.g., chef-led cooking demonstration) following sessions.</p> <p>Distribute the DHHL cookbook following a session.</p> <p>Consider webinars for session 2 when no data are collected.</p>
<p>Atlanta, GA</p> <ul style="list-style-type: none"> • Competing priorities • Finding locations to hold sessions • Difficult demographic to work with (e.g., pre-retirement) • Attracting enough facilitators 	<p>Train/retrain facilitators.</p>	<p>Match facilitators with expertise.</p> <p>Train at least two facilitators per position.</p> <p>Cross-train facilitators.</p>	<p>Expand facilitator roles.</p>	<p>Market the coalition in recruitment activities.</p> <p>Think outside the box (e.g., identify new venues for participants).</p>	<p>Enhance participant incentives.</p>
<p>Portland, OR</p> <ul style="list-style-type: none"> • Limited number in targeted community • Displaced AA community • Social isolation experienced by the targeted group • Limited number of health professionals as facilitators 	<p>Train additional facilitators.</p>	<p>Train young people to facilitate sessions.</p> <p>Retrain existing facilitators.</p> <p>Provide incentives to facilitators.</p>	<p>Expand facilitator roles.</p>	<p>Integrate into existing programs (e.g., HOLLA or Healthy Options to Live Longer Activity).</p> <p>Recruit during annual health fair (Wellness Village).</p>	<p>Employ a chronic disease self-monitoring model to the program.</p> <p>Expand the number of participants at each session to reach larger numbers.</p> <p>Provide participant incentives following each session.</p>

Louisville, KY <ul style="list-style-type: none"> ● Limited understanding of informed consent document ● Feelings of fatalism and myths related to colorectal cancer ● Lack of education in the community ● Too much scientific language 	Build on trusted relationship to appeal to committed facilitators.	Involve more facilitators. Train/retrain facilitator.	Expand roles, including a patient navigator.	Integrate EPICS into the statewide CRC screening program. Utilize FIT kits as follow-up to participant education.	Address reduction or elimination of resources. Include latest information on insurance coverage of screening.
					Partner with existing programs.

*DHHL=Down Home Healthy Living

Although the original protocol specified methods for the recruitment and training of facilitators, it was possible to make these modifications without altering the core elements of the intervention. One of the original facilitators commented, “Even though our training exceeded what was in the protocol, I’m certainly glad that I had it. I think the amount of training included in the protocol needs to be increased.”

RESULTS

The experiences described here demonstrate the feasibility of modifying a research protocol in a community-based participatory research project in order to respond to situations unique to the community. The EPICS protocol was modified in different ways in both Augusta and Philadelphia to respond to barriers to participant recruitment and retention with favorable results. In Augusta, 148 participants completed the project (original target: 144) and in Philadelphia, 393 participants completed the project (original target: 360). Most importantly, this was achieved while honoring two principles: the CBPR principle that the community is the senior partner in an academic-community partnership; and the research principle that the core elements of a research project must be retained if the protocol is modified.

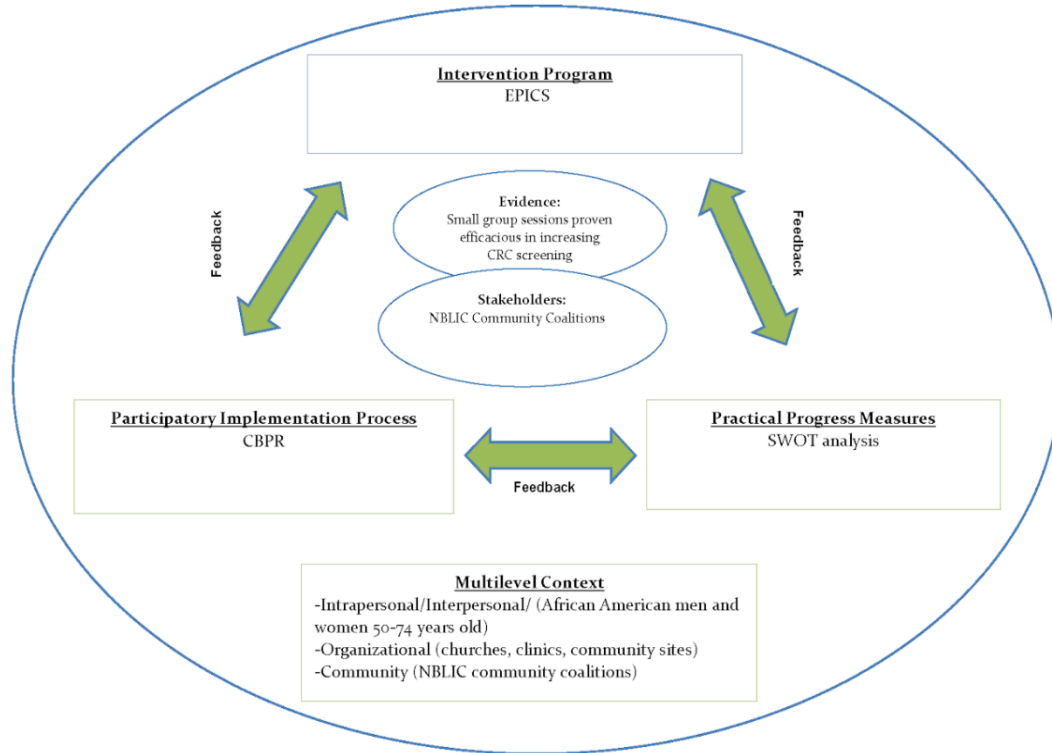
DISCUSSION

Building coalitions around a health or social issue has long been a tactic for community organization (Rodgers et al.,

2014). For addressing health disparities, coalitions in multi-sector partnerships can implement efforts targeting health-related behavior change (e.g., dietary intake, physical activity, tobacco cessation, and cancer screening) (Kegler and Swan, 2011; Dunne et al., 2013; Bornstein et al., 2013; Yeary et al., 2011). They can also target a variety of social determinants of health, such as housing, availability of affordable and nutritious foods, resources for physical activity (e.g., sidewalks and bicycle paths), public education, and transportation. To the extent that they adequately represent the communities from which they are drawn, community coalitions constitute entities with which academic researchers can negotiate and create partnerships for conducting community-based research projects.

But even when different communities are demographically similar, they are not monolithic in terms of priorities, values, or concerns. Research protocols for projects that are to be conducted at several sites may thus need to be adjusted accordingly, but in so doing, the core elements of the protocol must be retained. In this regard, application of the Evidence Integration Triangle (EIT) model developed by Glasgow et al (2012) may be helpful. The EIT describes integration of three components: an intervention program, a participatory implementation process, and practical progress measures. Its application is illustrated in Figure 1.

Figure 1. EPICS Evidence Integration Triangle (EIT) Model



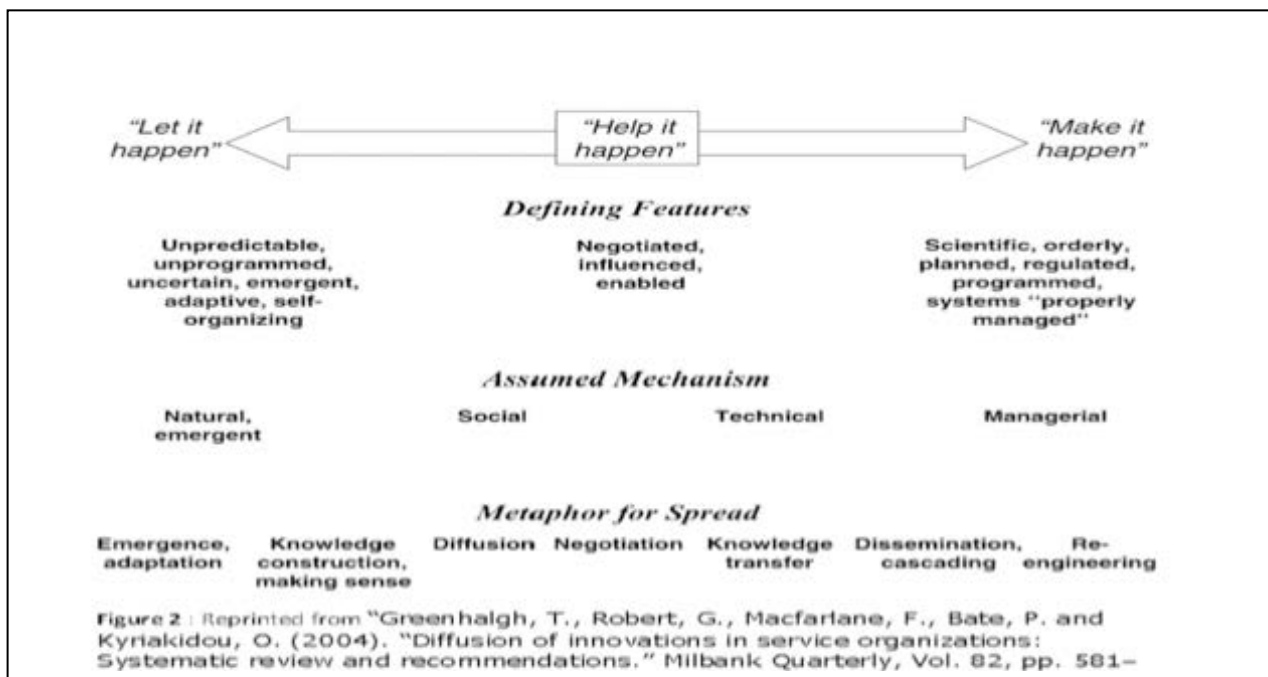
EPICS, Educational Program to Increase Colorectal Cancer Screening
 CRC, Colorectal cancer screening
 CBPR, community-based participatory research
 NBLIC, National Black Leadership Initiative on Cancer
 SWOT, strengths, weaknesses, opportunities, threats

The EIT is an ecological approach that is central to EPICS, which includes age-eligible AA men and women who are non-adherent to CRC screening guidelines (intrapersonal/interpersonal) and who are accessed through churches, clinics, and community sites (organizational) and educated by members of coalitions (community). CRC screening disparities and opportunities to educate affected communities is a starting point for delivering EPICS through a participatory process.

In many ways, this approach parallels the conduct of a multi-site clinical trial of a new drug. If the protocol for the trial must be approved by an institutional review board (IRB) at each site, it is likely that each site will be required to use a somewhat different consent form and some procedures may need to be modified. This, however, will not detract from the

validity of the trial if its core elements are retained and correctly implemented at each site. To avoid this issue, many such trials now utilize a central IRB. Although this may be appropriate for drug trials, it is not appropriate for community-based research in which the uniqueness of each participating community must be honored.

In our project, we were challenged by the need to alter the protocol in different ways at several sites while both remaining true to CBPR principles and preserving core elements of the intervention. Greenhalgh et al (2004) describe this as activities along a continuum between “let it happen” (whose defining features are unpredictable, unprogrammed, uncertain, emergent, adaptive, self-organizing) and “make it happen” (whose defining features are scientific, orderly, and planned) (Figure 2).



A traditional research project (laboratory or clinical) takes place at the "make it happen" end of the spectrum. However, the ideal location along this continuum in a CBPR project is "help it happen," whose defining features are negotiated, influenced, and enabled. This represents a collaboration between an academic partner and a community partner, with each partner contributing to a "help it happen" outcome. The key to success is trust – the ability of each partner to trust the other. Typically, the community partner does not trust the university, which may have a history of community exploitation in the name of research. The academic partner, for its part, often does not trust community priorities nor believe that the community can contribute to the execution of a rigorous research project. Building trust rarely happens quickly; in the case of the community coalitions in the EPICS project, it developed over the 30-year history of the NBLIC.

This, then, provides one response to the research gap, articulated in the form of a question, by Greenhalgh et al (2004): "By what processes are particular innovations in health services delivery and organization implemented and sustained (or not) in particular contexts and settings, and can these processes be enhanced?"

In the dissemination and implementation trial of EPICS, it is unlikely that differences in community values in the 15 participating communities are large, but the priorities of individuals in those communities may be. This would help explain why recruiting and training facilitators and recruiting and retaining participants is more challenging in one community than in another. Honoring the CBPR approach while preserving the requirements of traditional research methods enabled the creation of action plans tailored to each community while preserving the core elements of the intervention. This approach may prove useful to investigators conducting community-based research at multiple sites.

Our experiences with the Augusta and Philadelphia coalitions are representative of other discussions that took place with the other 13 coalitions participating in the EPICS project. However, each coalition and each discussion are unique; while the Augusta and Philadelphia experiences are illustrative of certain principles, they are not duplicative of other discussions with other coalitions.

Acknowledgements

The study is registered with ClinicalTrials.gov as NCT01805622. National Cancer Institute (1R01CA166785J01 and 5U54CA118638J07)

References

- American Cancer Society (ACS). (2016). *Cancer Facts & Figures for African Americans. 2016-2018*. Atlanta.
- Bandura A. (1986). *Social Foundations of Thought and Action. A Social Cognitive Theory*. Upper Saddle River, NJ: Prentice Hall.
- Blumenthal, D.S. (2006) A community coalition board creates a set of values for community-based research. *Prev Chronic Dis 3*: A16.
- Blumentha, D.S., Smith, S.A., Majett, C.D., et al. (2010). A trial of 3 interventions to promote colorectal cancer screening in African Americans. *Cancer 116*: 922-929.
- Bornstein, D.B., Carnoske, C., Tabak, R., et al. (2013). Factors related to partner involvement in development of the US national physical activity plan. *Journal of Public Health Management Practice 19*, S8-S16.
- Breslow, L. (1996). Social ecological strategies for promoting healthy lifestyles. *American Journal of Health Promotion 10*, 253-257.
- Colorectal Cancer Screening Intervention Program (rtips). Retrieved from <https://rtips.cancer.gov/rtips/programDetails.do?programId=1124686>.
- Community-Campus Partnerships for Health. *Principles of Good*

- Community-Campus Partnerships. Retrieved from https://depts.washington.edu/ccph/pdf_files/summer1-f.pdf.
- Cromley, E., Kleinman, L.C., Ramos, M.A., et al. (2011). A community-engaged approach to select geographic areas for interventions to reduce health disparities. *Prog Community Health Partnersh* 5, 299-305.
- Dunne, K., Henderson, S., Stewart, S.L., et al. (2013). An update on tobacco control initiatives in comprehensive cancer control plans. *Preventing Chronic Disease* 10.
- Glasgow, R.E., Green, L.W., Taylor, M.V., et al. (2012). An evidence integration triangle for aligning science with policy and practice. *American Journal of Preventive Medicine* 42, 646-654.
- Green, L.W., George, M. A., Daniel, M., et al. (2003). Guidelines for participatory research in health promotion. *Community-Based Participatory Research for Health*, 419-428.
- Greenhalgh, T., Robert, G., Macfarlane, F., et al. (2004). Diffusion of innovations in service organizations: Systematic review and recommendations. *Milbank Q* 82, 581-629.
- Howlander, N., Noone, A.M., Krapco, M., et al. (2014). SEER cancer statistics review, 1975–2011. Bethesda, MD: National Cancer Institute. Retrieved from http://seer.cancer.gov/csr/1975_2011/ Accessed on November 15,2015.
- International Collaboration for Participatory Health Research (ICPHR). Version: May 2013. Berlin: International Collaboration for Participatory Health Research; 2013. Position Paper 1: What is Participatory Health Research?
- Israel, B.A., Schulz, A.J., Parker, E.A., et al. (1998). Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health* 19: 173-202.
- Kegler, M.C., & Swan, D.W. (2011). An initial attempt at operationalizing and testing the Community Coalition Action Theory. *Health Educ Behav* 38, 261-270.
- Kluhsman, B.C., Bencivenga, M., Ward, A.J., et al. (2006). Initiatives of 11 rural Appalachian cancer coalitions in Pennsylvania and New York. *Prev Chronic Dis* 3, A122.
- Lansdorp-Vogelaar, I., Knudsen, A.B., & Brenner, H. (2011). Cost-effectiveness of Colorectal Cancer Screening. *Epidemiologic Reviews* 33, 88-100.
- Lansdorp-Vogelaar I, Kuntz, K.M., Knudsen, A.B., et al. (2012). Contribution of screening and survival differences to racial disparities in colorectal cancer rates. *Cancer Epidemiology Biomarkers & Prevention* 21, 728-736.
- Lee, S.Y., Arozullah, A.M., & Cho, Y.I. (2004). Health literacy, social support, and health: A research agenda. *Soc Sci Med* 58,1309-1321.
- Raine, K.D., Sosa Hernandez, C., Nykiforuk, C.I., et al. (2014). Measuring the progress of capacity building in the Alberta Policy Coalition for Cancer Prevention. *Health Promot Pract* 15, 496-505.
- Rodgers, K.C., Akintobi, T., Thompson, W.W., et al. (2014). A model for strengthening collaborative research capacity: illustrations from the atlanta clinical translational science institute. *Health Educ Behav* 41, 267-274.
- Rogers, E.M. (2003). Diffusion of innovations, New York: Free Press.
- Satcher, D., Sullivan, L.W., Douglas, H.E., et al. (2006). Enhancing cancer control programmatic and research opportunities for African-Americans through technical assistance training. *Cancer* 107, 1955-1961.
- Smith, S., Johnson, L., Wesley, D., et al. (2012). Translation to practice of an intervention to promote colorectal cancer screening among african americans. *Cts-Clinical and Translational Science* 5, 412-415.
- Smith, S.A., Whitehead, M.S., Sheats, J.Q., et al. (2015). Community-based participatory research principles for the African American community. *J Ga Public Health Assoc* 5: 52-56.
- U.S. Cancer Statistics Working Group. United States Cancer Statistics: 1999–2014 Incidence and Mortality Web-based Report. Atlanta (GA): Department of Health and Human Services, Centers for Disease Control and Prevention, and National Cancer Institute; 2017. Retrieved from <http://www.cdc.gov/uscs>.
- Yeary, K.H., Mason, M., Turner J, et al. (2011). A community-based approach to translational research addressing breast cancer disparities. *Transl Behav Med* 1: 224-233.

© Selina A. Smith, MDiv, Joyce Q. Sheats, Sandra J. Hamilton Mary S., Ernestine P. Delmoor, Thomas Britt, Cassandra L. Harris, Janette Robinson-Flint, Cheryl A. Johnson, Corliss McKeever, Connie L. Sorrell, Vincent R. Green, John W. Harmon, Dorothy L. Reddic, Jane Giddens-Cabarrus, Shirley Jordan-Seay, Benjamin E. Ansa, and Daniel S. Blumenthal. Originally published in jGPHA (<http://www.gapha.org/jgpha/>) October 25, 2019. This is an open-access article distributed under the terms of the Creative Commons Attribution Non-Commercial No-Derivatives License (<http://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work ("first published in the Journal of the Georgia Public Health Association...") is properly cited with original URL and bibliographic citation information. The complete bibliographic information, a link to the original publication on <http://www.gapha.jgpha.org/>, as well as this copyright and license information must be included.

Appendix 1

The seven guiding principles of CBPR for the African American Community (Smith et al., 2015):

1. We are family. This is the title and refrain of a 1977 hit song recorded by the group Sister Sledge. The song is a classic in the pop music world, perhaps because it is a kind of theme song for community solidarity. It thus represents research that is community-based (not community-placed) and supported by the community as a whole. CBPR provides a cooperative framework for working toward a common goal.
2. It takes a village. The African proverb, “It takes a village to raise a child” became well known as the title of a book written by then-First Lady Hillary Rodham Clinton in 1996. In the context of CBPR principles, it represents the mutual trust established between investigators, stakeholders, and the community so that all partners function as if they constituted a village. The ‘village’ facilitates co-learning, shared decision-making, and mutual ownership of the problem and its solutions. A growing consensus is that, for translation of evidence-based interventions, they must be implemented with methods engaging partners and stakeholders that treat their expertise and perspectives with equal weight to those of researchers.
3. Come as you are. This phrase, originally a party invitation, has been used in popular as well as gospel music. It describes our call to the community and indicates the willingness of academic researchers to meet their community partners on their own turf and on their own terms. It rejects the proposition that the community must assume a posture of “readiness” in order to participate equitably in the research process. For scientists and community leaders, the goal is to enhance communities by empowering them to become full participants in research.
4. Just stand. This is a refrain from a gospel song. In the CBPR context, it points out that current research ‘stands on’ or is grounded in past research. With each new research cycle, new questions are expected to emerge from the research itself. Such an approach is cyclic, converging on a better understanding of processes as well as outcomes.
5. Health, wholeness & healing. This reflects the fact that most communities have little interest in being studied; however, they are concerned about education, jobs, health care, and other services – entities that will improve community health. Research must ensure that individuals have the opportunities, knowledge, attitudes, and skills needed for optimal health. Researchers who wish to conduct observational studies must be able to describe how their research will lead to an intervention or policy change that will improve community health.
6. Go tell it on the mountain. This is the title and refrain of a Negro Christmas spiritual. It reminds us of the role of the community in disseminating the results of CBPR, including scientific publications (which may be of less interest to the community), the popular media (e.g., newspapers, radio, organizational newsletters, and magazines), and policymakers.
7. We shall overcome, someday. The civil rights anthem brings to mind the overriding goal of CBPR in the African-American community: reducing and eliminating the health disparities that plague this community. Mortality rates for African Americans are higher than those for other racial and ethnic groups for major causes of death. This must be overcome. This principle is relatively unique to NBLIC, partly because it reflects outcome rather than process and partly because it focuses particularly on racial/ethnic health disparities