

## Increasing Access to Clinical and Educational Studies

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**CONDENSED ABSTRACT:** The Increasing Access to Clinical and Education (ACES) Project was an initial step to address cancer health disparities in the African-American community in Philadelphia. This effort involved establishing an operational infrastructure for the program, recruiting and mentoring special populations investigators, conducting pilot research studies, and leveraging support for ongoing activities. Lessons learned from the ACES Project can guide the adaptation and dissemination of cancer prevention interventions in community-based settings.

## **ABSTRACT**

**Background:** In 2001, the National Cancer Institute (NCI) provided funds to support the Increasing Access to Clinical and Educational Studies (ACES) Project of the Thomas Jefferson University, Kimmel Cancer Center in Philadelphia. The ACES Project enabled the Center to engage in to the systematic development of approaches for reducing cancer health disparities among African-Americans in Philadelphia.

**Methods:** The ACES Project brought together community partners, clinical partners, cancer prevention and control experts, and staff from an NCI-designated cancer center to develop and implement a community-based outreach education program, a special populations investigator (SPI) training program, and SPI pilot studies in cancer screening and clinical trials participation.

**Results:** At the end of five years, the ACES Project had: 1) organized a steering committee, expert panel, and a network of community collaborators and clinical partners; 2) implemented a clinical trials education program for community-based nurses, lay health advocates active in community organizations, and health ministries in community churches; 3) mentored four SPIs in cancer prevention and control research; 4) completed SPI pilot studies; and 5) leveraged these activities to gain support for cancer health disparities-related research.

**Conclusions:** The ACES Project established a successful dialogue between an NCI-designated cancer center and the African American population related to cancer research and enabled SPIs from the community to adapt evidence-informed interventions for application in cancer prevention and control research. Lessons learned from the ACES Project can guide the implementation of such projects in the future.

**KEY WORDS:** Community Health Networks, African-Americans, cancer, prevention and control, behavior, clinical trial, training, educational activities, community outreach, interventions.

## INTRODUCTION

In 1999, the National Cancer Institute (NCI) issued a call for applications in response to an announcement titled, “Special Populations Networks for Cancer Awareness Research and Training” (CA-99-003). Of those applications submitted in response to this announcement, the NCI funded 18 special populations networks (SPNs) across the United States. Funding for the SPNs was intended to support efforts aimed at establishing an “infrastructure to promote cancer awareness within minority and medically underserved communities, and to launch from these more research and cancer control activities aimed at specific population subgroups”.<sup>1</sup>

The “Increasing Access to Clinical and Educational Studies” or ACES Project SPN, was funded in 2001. With support provided by this NCI initiative, the Kimmel Cancer Center (KCC) of Thomas Jefferson University took steps to: 1) establish a cancer education and research infrastructure to guide and support the project, 2) deliver a cancer clinical trials outreach education program to African American community-based organizations in Philadelphia, 3) identify and train African American researchers as special populations investigators (SPIs), and 4) carry out SPI pilot research studies. This effort was conceived as a preliminary step towards developing a full-fledged program of community-based participatory research (CBPR) with the African American community in Philadelphia.

Despite Philadelphia’s abundant health care resources and the efforts of its health care providers, many residents experience health disparities. These residents may be described as “special populations.” This term refers to certain groups (e.g., racial and ethnic groups, the medically underserved, as well as those with low income and low literacy skills) that collectively have increased cancer incidence or mortality or have decreased survival.

Overall, Philadelphia has significantly higher than expected cancer incidence and mortality rates than the Commonwealth of Pennsylvania as a whole; and, as shown in **Table 1**, black males and females residing in Philadelphia experience higher cancer incidence and mortality rates than their white counterparts.<sup>2-3</sup> The ACES Project focused attention on increasing community awareness related to cancer research in general and about cancer clinical trials in particular. Attention was also directed to the development of approaches that could be used to reduce disparities related to breast and prostate cancer morbidity and mortality.

In this paper, we describe the development and implementation of a project that supported the design and development of the cancer outreach education program and SPI research. The developmental process involved gatekeeper and key informant interviews, focus groups with lay members of the community, and formative evaluation involving community-based health care professionals and national experts in cancer prevention and control research. By engaging such key actors in developmental activities, we intended to increase the likelihood that methods and materials ultimately would be suitable for use in community and practice settings.<sup>4</sup> Further, we provide information on funding leveraged as a result of the ACES Project.

## **METHODS**

The ACES Project, in both its community outreach and research activities, has had to meet three major challenges: 1) establish an infrastructure that could support outreach education and cancer prevention and control research, 2) deliver cancer outreach education to community-based organizations, 3) prepare SPIs to conduct cancer prevention and control research that is relevant to the African American population.

## **Establishing the ACES Project Infrastructure**

In order to develop a cancer education and research infrastructure, the ACES Project constituted a steering committee, an expert panel, community collaborators, and clinical partners. Steering committee members included individuals in the Philadelphia area who were involved in the health care of African-Americans, were familiar with cancer prevention and control, and could provide a lay perspective on research involving the African American population. The steering committee met regularly to review and provide direction on all ACES Project activities. The expert panel included the following nationally prominent individuals with experience in cancer education and research with African American populations: Drs. Ronald Braithwaite, Sandra Millon Underwood, and Sherry Mills. The panel met at least three times a year and advise the ACES Project Principal Investigator and the steering committee on issues related to recruiting and training minority scientists and developing pilot studies. Expert Panel members participated regularly via teleconference in Steering Committee meetings.

The ACES Project clinical partners were health care sites that provided access to patient populations eligible for project pilot studies. Community collaborators for the ACES Project included the National Cancer Institute's Cancer Information Service (CIS) and community-based organizations. These community collaborators helped develop and implement the outreach education program, and partnerships were developed with community-based organizations.

### **Developing an Outreach Education Program**

The ACES Project developed an outreach education program, entitled *Who Is Missing Out?* that addressed both factual and attitudinal issues related to cancer research and clinical trials. The program sought to present accurate information in plain language, discuss the historical and contemporary experiences of community members with the health care system,

and ensure that participants would make informed decisions about medical research and clinical trials (e.g., risks and benefits of participation). Importantly, the program was not designed to recruit participants into specific research studies. ACES project staff worked collaboratively with the Cancer Information Service's Mid-Atlantic Region partnership program in developing the content and format of the program. Other collaborators participated in a formative evaluation of the program's content and format as well as pre-testing the program with members of community organizations.

Initially, the *Who Is Missing Out?* program consisted of two 90-minute sessions presented about 1 month apart. An outline of program content is shown in **Table 2**. Session 1 addressed information on cancer health disparities, medical research, and clinical trials. Attitudes and beliefs that affect informed decision making related to clinical trials participation were also examined. Session 2 discussed information about attitudes and perceptions toward cancer research studies gathered by participants from members of their community between the sessions. Participants discussed their findings and compared them to the information presented in the first session and their own prior beliefs about cancer research. The use of educational resources such as the NCI Cancer Information Service were also discussed as a way to create situations in which patients can make informed decisions.

Before the first session, potential participants were sent an invitation letter from their community partner organization and were asked to complete an educational needs assessment. Recipients were asked to return the completed assessment form to a designated individual in the partner organization before the program date. Information obtained from this form gave presenters valuable advance insight into the backgrounds of program participants. Individuals who did not return a completed needs assessment prior to the program date were asked to

complete the form when they arrived for the first session. At this session, attendees were informed that participation involved a follow up telephone survey administered 3 to 4 months after the session. These surveys were accepted anonymously if participants chose not to reveal their identities.

### **Preparing Special Populations Investigators to Conduct Research**

An important component of the ACES Project focused on engaging Special Population Investigators (SPIs) in cancer prevention and control research. The process began by identifying African-American professionals who had academic preparation and interests consistent with taking leadership roles in cancer prevention and control research. Even before a formal relationship was established, the ACES Principal Investigator acted as a mentor to potential SPIs, helping them to consider how the ACES project would or would not contribute to their career goals and explore how their current professional activities could be linked to cancer prevention and control research.

Interested candidates were asked to prepare a 2-page concept paper about a pilot study that could be done with ACES Project support. The concept paper also addressed the nature and extent of resources needed to carry out the proposed project. Members of the Steering Committee then assessed the candidates' concept papers for scientific merit, potential to contribute to the reduction of cancer health disparities, and feasibility. Once approved by the steering committee, participants received further mentoring from the ACES Project Principal Investigator and technical assistance from ACES project staff in developing a proposal for a pilot study grant.

As part of their training experience, SPIs also worked closely with ACES Project staff to develop pilot project intervention materials, refine the study protocol, and develop data



collection instruments. SPIs also become familiar with research study administrative and management issues such as budgets, human subjects protection requirements, and institutional and NIH-required forms and procedures for submission and completion of grants. SPIs also were required to present oral progress reports to the steering committee at regularly scheduled meetings. This process culminated in preparation and submission of a pilot study proposal that specified pertinent research question(s), employed an appropriate research design, described study procedures, and presented data management and analysis plans. The proposal was initially submitted to the NCI Center to Reduce Cancer Health Disparities for support.

Funded projects involved developing methods that could be used to improve cancer care or enhance decision making related to clinical trials participation. The studies were designed to test novel strategies and methods that had not previously been used with African-American populations. Before being tested in the pilot studies, the interventions were pre-tested with community-based organizations and individuals, testing the utility of plain language and the cultural appropriateness of the approaches employed.

## **RESULTS**

The ACES Project infrastructure was sustained over the life of the project. The *Who Is Missing Out?* program was delivered in the community through community-based nursing organizations, churches, health ministries, and health advocacy organizations, and evolved to accommodate programming needs of interested organizations. Special population investigators, with the support of project staff and oversight of the steering committee, successfully completed 3 pilot research studies. Further, the ACES Project leveraged funds to generate additional support for these activities.

### **ACES Project Infrastructure Activities**

The Steering Committee held regularly scheduled face-to-face meetings to provide oversight for the ACES Project. Members of the Expert Panel joined these meetings by teleconference. Steering Committee and Expert Panel members maintained a high level of interest and active participation in the meetings; and, there was little turnover among the members. During the course of the project, additional representatives were added with backgrounds in health advocacy and community-based organizations in the African-American community. Because of the continuity of the Steering Committee and Expert Panel membership and their familiarity with the outreach education and the pilot studies, useful and important suggestions related to the logistics of pilot studies, the implementation of outreach education, and even the interpretation of data were forthcoming. The lay members were supportive but very practical in their suggestions, giving priority to how cancer and medical research is perceived of and experienced in the community.

### **Outreach Education in the Community**

ACES Project staff and CIS personnel worked closely with community partner organizations to bring the program to their members. The initial audience of the program was community-based nurses and lay health advocates. These participants had opportunities to share their knowledge and experience with others in the community. Over time, as interest in the program evolved, it was adapted to a general community-based audience because of increasing interest from a wider audience. Nonetheless, the guiding principles of the program remained the same.

Outreach to potential community partners involved referrals from members of the ACES steering committee, the Cancer Information Service, and ACES project staff. Initial contacts were made with organization leaders, usually followed by brief informational presentations to executive board or program committee members. After this meeting, a letter from the ACES Principal Investigator was sent, formally inviting the organization to become a partner in the effort to reduce cancer health disparities. Memoranda of understanding were developed between agencies that specified tasks, resources to be shared, and other program logistics. The ACES Project outreach education activities are summarized in **Table 3** in terms of the organizations and audiences contacted. As indicated in the table, a substantial amount of effort was devoted to the conduct of educational events that reached out to the health ministry leadership of area churches. Interestingly, project staff members reached a large radio listening audience with a presentation on the *Who is Missing Out?* Program and were invited to present the Program at national and international meetings of professional associations.

### **Special Populations Investigator Research**

Four SPIs received training and technical support from ACES Project staff. Each SPI submitted a pilot study grant application to the Center to Reduce Cancer Health Disparities (CRCHD) 3 of which were awarded funding:

- *Preparing African American Women for Breast Biopsy*. Submitted by Patricia K. Bradley, PhD, RN, CS. Funded by CRCHD. Completed in 2004.
- *Informed Choice Among African American Men About the Negative Biopsy Trial*. Initially submitted by Kathleen Jennings-Dozier, RN, MPH, PhD (deceased). Work continued by Ernestine Delmoor, MPH. Funded by CRCHD. Completed in 2005.

- *Acceptability and Feasibility of Decision Counseling for Clinical Trials Participation*. Submitted by Deborah Witt, MD. Funded by CRCHD. Completed in 2005.
- *Informed Decision Making Among African American Women About Participating in a Breast Cancer Prevention Clinical Trial*. Submitted by Joretha N. Bourjolly, MSW, PhD. Submitted in 2002, but not funded by CRCHD.

The purpose, study population, and components of the intervention employed in each of the funded pilot studies are shown in **Table 4**. Outcome measurements, results, and conclusions of each pilot study are shown in **Table 5**. Two of the studies demonstrated the effectiveness of an intervention.

It is difficult to overcome many of the psychological, social, and cultural barriers created by this setting. The logistics of these pilot studies made proximity to the Thomas Jefferson University Hospital (TJUH) clinical services a high priority. As a tertiary urban medical center, TJUH provides services to many members of special populations. Future studies, informed by the results of these pilot studies, must place higher priority on settings in the community and overcome logistical barriers through partnerships with community-based organizations.

### **Leveraged Funding**

Funding from the ACES Project has generated additional support for cancer health disparities-related research. This support includes *Informed Decision Making about Participation in Cancer Prevention Trials*, a 4-year study funded by the Commonwealth of Pennsylvania Department of Health to develop an educational intervention to facilitate decision making about enrollment in prostate cancer prevention trials. In addition, *Decision Counseling about Clinical Trials Participation* is a 3-year subcontract funded as part of the Fox Chase

Cancer Center Community Clinical Oncology Program Research Base for Cancer Prevention and Control to develop a prototype decision counseling protocol to facilitate decision making about clinical trials participation that is adaptable to specific clinical trials.

## **DISCUSSION**

The ACES Project succeeded in: 1) developing a collaborative infrastructure to guide research; 2) preparing investigators who were familiar with population to conduct research aimed at developing interventions to address cancer prevention and control needs; and 3) testing the interventions in practice. Along the way, important lessons were learned that prepared ACES to make additional strides.

**Lesson 1. It is important to engage knowledgeable community representatives early and often in interactions with researchers and project staff in the planning of interventions and programs.**

During the course of the ACES Project, a steering committee was formed and held regularly scheduled meetings (3 per year). The purpose of this committee was to advise the project team on the planning and implementation of the *Who Is Missing Out?* program; selection and training of special populations investigators (SPIs); and SPIs proposed pilot studies.

An expert panel was convened to guide the research efforts of the ACES Project. Members of the expert panel were regular, active participants in steering committee meetings and provided input to program staff on education outreach program form and content. These committees reviewed pilot study research proposals prepared by the SPIs. The attendance of steering committee and expert panel members at regularly scheduled project meetings and the willingness of these individuals to participate in a number of ad hoc conference calls were remarkable. The collective participation of these committed participants generated insights and

recommendations that served to ground the outreach education program and strengthen the scientific rigor of the pilot research studies proposed.

**Lesson 2. Culturally relevant and feasible programs need to consider the perceptions of the targeted population with regard to proposed methods and materials. Acceptance of this effort is facilitated by perceptions about the motivations of intervention sponsors.**

ACES Project staff worked closely with community collaborators to design and deliver the *Who is Missing Out?* Program. To enhance the chances of success existing, Clinical Trials Education Series (CTES) materials were adapted and new educational materials related to cancer clinical trials were developed. The involvement of individuals with experience in designing, pretesting, and pilot testing low-literacy materials and in creating cancer clinical trials educational information materials was helpful in including program content that would be interesting and engaging. It also called for a labor-intensive, collaborative approach to obtaining approval from community partners for program presentation, memoranda of understanding related to program participation, scheduling of times and venues for program delivery, provision of the 2-part program to participants, collection of data on program implementation, and analysis of collected data.

It was also necessary to receive IRB approval to deliver the outreach education program, since it was associated with a funded study. Leaders of community organizations were receptive to an outreach education program that could be delivered in a manner that was compatible with the interests and needs of organization members and organizational priorities. Future work should be directed towards tailoring the program for delivery to community populations in

relation to a variety of cancer prevention and control opportunities (e.g., cancer screening, clinical trials, and genetic testing for cancer susceptibility).

**Lesson 3. Sustained mentoring and ongoing support are vital to successful preparation of SPIs to engage in research.**

The ACES Principal Investigator and staff supported SPIs in the development and implementation of their pilot research studies. This effort included providing guidance and assistance in designing the proposed study interventions, specifying research hypotheses, preparing the pilot study grant applications, addressing budget issues, obtaining IRB approval, collecting and managing data, performing statistical analyses, and interpreting research findings. Identifying persons who had institutional support for developing research careers was an important element of SPI selection. To increase the likelihood of their success, it was necessary to provide SPIs with access to individuals experienced in research methods, data collection and analysis, proposal writing, grant budget management, staff training and supervision, intervention implementation, report preparation, and manuscript development and submission. SPIs maintained regular interaction with the ACES Project team. A substantial commitment of time and energy of the SPI and the project team was needed to carry the pilot studies to fruition.

**Lesson 4. Mentored SPIs conducted pilot research projects that resulted in the identification of promising cancer prevention and control behavioral intervention methods and materials.**

The study entitled *Preparing African American Women for Breast Biopsy* showed that African-American women who were referred for breast biopsy experienced concerns about the biopsy procedure and the consequences associated with undergoing the procedure. Results of the study indicate that educational counseling can enhance participants' biopsy-related knowledge,

improve response efficacy, and increase perceived social support. Results of another pilot study, *Informed Choice among African American Men about the Negative Biopsy Trial*, showed that many men will participate in a decision counseling session related to clinical trial participation. The study also showed that there was a high level of clinical trial participation among those men who underwent decision counseling.

Collaborative relationships were established between the ACES Project and the Breast Imaging Center of Thomas Jefferson University Hospital and the Department of Radiology and the TJUH Department of Urology in order to facilitate conduct of these studies. This effort was intended to develop methods and materials that were scientifically sound and efficacious, thus setting the stage for adaptation and evaluation in community settings.

The third pilot study, *Acceptability and Feasibility of Decision Counseling for Clinical Trials Participation*, was conducted with congregation members of a large African-American urban church. Findings from the study showed that African-American churchgoers may be likely to use a decision counseling service when such an intervention is integrated into community settings that are used to access routine care. Study participants were also receptive to the notion of partnership with researchers from an academic medical center in collaborative research of interventions to improve health care among people in the community.

**Lesson 5. Movement towards the development of promising cancer prevention and control interventions can be accomplished via the establishment of infrastructure, implementation of community outreach education, and mentoring of promising SPIs. The processes of rigorously testing new intervention methods and materials and of adapting evidence-based approaches for use in community-based settings are**



**fundamental next steps that need to be taken in order to impact cancer health disparities in a meaningful.**

CBPR research in the areas of cancer prevention and control should involve community members, their representatives, and researchers in a sustained effort to address cancer health disparities. This partnership ideally involves conceiving, designing, and conducting research studies; analyzing and interpreting research findings; and communicating research results to constituents. In the end, the goal of such a partnership is to implement effective, evidence-based interventions in community settings in order to realize meaningful reductions in cancer health disparities. Realizing this goal requires a substantial and sustained commitment to achieving high levels of intervention program “fidelity” (degree of scientific integrity of the program) and “fit” (degree of consistency with the culture of the community).<sup>5,6</sup>

## **CONCLUSIONS**

The approach outlined above can serve to engage community populations in the creative process of addressing the cancer health disparities that are experienced every day. In the Philadelphia area, this process should involve 1) broadening the existing cancer education and research infrastructure to serve state or regional geographic areas; 2) conducting cancer outreach education and disparity reduction demonstration projects (e.g., breast, colorectal, and prostate cancer screening and clinical trials participation) in the community; 3) identifying special populations investigators to be trained and supported in CBPR related to cancer prevention and control; 4) expanding CBPR activities to include developing community partnerships that focus on dissemination; that is, translation of evidence-based interventions into ongoing programs and practice; and 5) using dialogues with health care providers, insurers, and public health care agencies as another opportunity to support community involvement in dissemination. While the ACES Project achieved much, the results of this effort highlight the importance of continuing to

work towards achieving a cultural synthesis related to the integration of cancer prevention and control interventions into routine care. In sum, the ACES Project has paved the way for taking the crucial third step along the CBPR pathway—moving evidence-based interventions into practice.

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Table 1. Cancer Incidence and Mortality Rates in Pennsylvania (PA) and Philadelphia<sup>2</sup>

	Overall		Male		Female	
	PA	Philadelphia	PA	Philadelphia	PA	Philadelphia
Incidence, all sites *	498.4	546.4				
Whites	489.1	540.2	576.7	643.9	433.4	482.7
Blacks	528.9	540.9	710.1	740.0	416.0	421.4
Mortality, all sites§	204.8	252.9				
Whites	200.7	238.6	251.1	296.5	169.4	204.3
Blacks	269.2	285.1	360.9	391.3	217.9	228.1

\* All cancer sites, 1999-2001 cases per 100,000.

§ All cancer sites, 1998-2002 deaths per 100,000.

Table 2. Content of the *Who is Mission Out?* Program

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<b><i>Content Overview</i></b>	
<b><i>Session 1</i></b>	
Presentation	Historic and cultural context of medical research in the African-American community Cancer health disparities and the African-American population of Pennsylvania
Discussion	Sources of the unequal burden of cancer
Interview	Meet “Mrs. Martin,” a community member with questions about a breast cancer prevention clinical trial. The role of Mrs. Martin was taken by one of the presenters.
Presentation	Impact of past clinical trials on health of the community Interaction of medical research and reducing cancer health disparities
NCI Video	Segment from <i>Cancer Clinical Trials: An Introduction for Patients and Their Families</i>
Presentation	Key medical research concepts Clinical trials—ethical and scientific standards Human subjects protection—Federal laws and regulations Informed consent process
Video	Segment from <i>African American Women CAN Beat Breast Cancer</i>
Discussion	Taking part in clinical trials—benefits and risks Reasons to participate or not participate What do communities and individuals need to know to make informed decisions about clinical trials?
Presentation	Prepare for activity between Session 1 and Session 2—talking about clinical trials with people in the community
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<b><i>Session 2</i></b>	
Presentation	Review key concepts—ethical and scientific research standards, human subjects protection, and informed consent process
Activity	Small groups (2-3 persons) tabulate responses of community members collected by participants between Sessions 1 and 2
Discussion	Compare actual responses by community members to initial perceptions of participants
Presentation	Finding reliable information about cancer clinical trials (e.g., Cancer Information Service)
Discussion	Inclusion of these topics in ongoing activities of participants

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Table 3. Outreach Education Activities

Organizational Setting	Educational event settings	Estimated membership	Educational events <sup>1</sup>	Audience participation
Churches (Health Ministry and other lay leadership)	80	27,250	12	381
Community-based health advocate organizations	2	1,400	2	46
Area hospitals	2	24	2	35
Other community-based organizations	3	4,100	4	76
Local radio stations with predominantly African American listening audience	1	n.a.	1	79,000
National and international meetings of professional societies	3	n.a.	3	155

<sup>1</sup> Presentations on *Who is Missing Out?* clinical trials outreach education program

n.a. Not available