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ORIGINAL PAPER

# Developing a Partnership Model for Cancer Screening with Community-Based Organizations: The ACCESS Breast Cancer Education and Outreach Project

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**Abstract** There is growing enthusiasm for community-academic partnerships to promote health in underserved communities. Drawing upon resources available at a comprehensive cancer center, we developed the ACCESS program to guide community based organizations through a flexible program planning process. Over a three-year period, ACCESS partnered with 67 agencies serving various medically underserved populations. Organizations included hospitals, parishes, senior centers, harm reduction programs, and recreational facilities. Program outcomes at the organizational level were quantified in terms of introduction of new cancer information, referral or screening programs, as well as organizational capacity building. ACCESS represents a viable model for promoting partnership to transfer behavioral health programs and adapt interventions for new audiences. Plans to further evaluate and enhance this model to promote cancer screening efforts are discussed. We argue that, ultimately, formation and development of community partnerships need to be understood as a fundamental area of practice that must be systematically integrated into the mission of major academic medical institutions in every area of public health.

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## Introduction

Partnerships with community organizations are a central focus of efforts to reduce breast cancer morbidity and mortality. For women over age forty, current recommendations call for a decades-long regimen of self-care and screening (American Cancer Society, 2001). Personal and practical challenges to maintaining this regimen differ depending upon age, culture, health history, socioeconomic status, availability of service, and a host of other factors. As in most areas of public health, when it comes to cancer awareness and screening, one size does not fit all. Partnerships make it feasible to craft sustainable educational, behavioral, and structural interventions that respond to the particular barriers, concerns, and strengths of diverse communities.

Over the past five years, we have developed the ACCESS cancer education and outreach project to promote early detection of breast cancer through partnerships with community-based organizations (CBOs). The ACCESS project was designed to identify community partners, document specific needs of organizations' clients and constituents, raise CBOs' knowledge of the benefits of early cancer detection, explore roles that a given CBO can play in the continuum of access and care, and provide technical assistance to help organizations respond to the problem of cancer. As we shall document below, this work has helped to attract new agencies to the fight against cancer and has started to yield answers to key questions about partnerships.

## Background

### Cancer risk behaviors and screening among medically underserved groups

Studies by Rajkumar and Hartmann (1999) and Ringash and the Canadian Task Force on Preventive Health (2001) show that the "medically underserved" are a diverse and changing population. Women once considered to be at highest risk for developing breast cancer (e.g., older women, those with a family history) are increasingly adhering to screening practices and some disparities are decreasing (Black, Stein, & Loveland-Cherry, 2001; Lewis et al., 2001). For example, rates of screening among African American women have improved markedly over the last decade. In the American Cancer Society's 2001 Early Detection & Prevention Facts & Figures report, data show that compared to Caucasian women, African American women have higher rates of utilization for most screening procedures. Among African American women, rates of regular mammography and other cancer screening tend to be related to income and education (Champion & Menon, 1997; Jones, Culler, Kasl, & Calvocoressi, 2001; Miller & Champion, 1997; Siegel et al., 2001). In contrast, Latinas are less likely to have a mammogram or clinical breast exam than both African American and Caucasian women (Paskett, Rushing, D'Aostino, & Tatum, 1997; Roetzheim et al., 1999).

These and similar findings suggest the need for a more fine-tuned definition of "medically underserved" in respect to early breast cancer detection. Three groups of particular concern include women: (1) who have household income of less than $20,000 a year; (2) who have lower educational background (completion of less than high school); or (3) who live in areas that have insufficient medical facilities (Kiefe et al., 2001; Newman et al., 2001; Reisch, Barton, Fletcher, Kreuter, & Elmore, 2000; Theuer et al., 2001). Additional efforts are necessary to reach groups with special needs and circumstances, due to factors such as immigrant status, religion or occupation as well as compounding problems such as chronic illness, psychiatric disorders, institutionalization, or substance use (Danigelis, Worden, & Mickey, 1996; O'Malley, Earp, & Harris, 1997; Phillips & Wilbur, 1995; Underwood, Shaikha, & Bakr, 1999).

### Partnerships for breast cancer screening

In New York State, as in other states, the concept of involving community organizations in breast cancer outreach and screening has been realized through partnership programs sponsored by the Centers for Disease Control and Prevention (CDC) under the federal Breast and Cervical Cancer Mortality Prevention Act of 1990 (Public Law 101-354). This Act makes provisions for community partnerships and coalition building to reach underserved women. The New York State Department of Health's Healthy Women Partnership (NYS DOH Partnership) (2002) has established 53 lead partnerships in counties throughout the state. These lead partners including local departments of health, clinical centers and American Cancer Society chapters are given the task of reaching out to other community-based organizations. These "outreach partners" are asked to help refer women to "provider partners," clinical sites available to provide low or no-cost mammograms and related clinical services. The Partnership program focuses on women over age 40 living at or below 250% of the federal poverty level and who are uninsured or not covered for cancer screening.

As of February 2002, the NYS DOH Partnership formed ties with 2,334 agencies statewide. Partners include community organizations such as churches, schools, senior centers, youth clubs, voluntary service associations, advocacy groups, health and wellness settings, and social service agencies that are part and parcel of community life and have an established track record of working with groups requiring improved access to preventative health services and screening. The program screens approximately 60,000 women per year (approximately 18% of women estimated to be eligible in the state). Consistent with CDC guidelines, most funds in this program are used to pay medical costs for screening and follow-up treatment of women. Few resources are earmarked to help CBO partners carry out outreach. Even so, NYS DOH and local lead partners are responsible for documenting outreach efforts as well as screening referrals (CDC, 2002; NYSDOH, 2002).

### Community-based organizations as mediating structures

This idea of improving public health by mobilizing local community organizations able to translate new innovations to specific communities is consistent with Berger and Neuhaus' (1996) discussion of empowerment. These authors state that public policy goals (including health promotion) can best be accomplished by identifying agencies in underserved communities able to mount services that respond to the needs and preferences of specific clientele. Berger and Neuhaus refer to such agencies as "mediating structures" because they intercede between the needs of individuals in a specific locality and institutional bureaucracies (i.e., federally-supported public health programs) charged with addressing those needs at a societal level. They emphasize that mediating structures should be accountable for achieving desired outcomes, although the strategies employed can and should be determined by local circumstances and cultures. In general, mediating structures are designated to receive the resources to accomplish public health goals but maintain the autonomy necessary to respond effectively to community needs (Ribisl & Humphreys, 1998).

## The need for community-academic partnerships to support mediating structures

The concept of community-academic partnership can be fruitfully linked to the development of mediating structure (Hayden, Veith, Thomas, Austin, & Moore, 1997). CBOs recruited through efforts like the NYS DOH Partnership, including religious institutions, schools, senior centers, voluntary associations, clinics, and social services, often have close, long-term relationships with medically underserved segments of the community. However, in order for such CBOs to function effectively as mediating structures, necessary capacities must be in place or developed and resources must be made available. To be effective in promoting cancer screening, a CBO requires sufficient medical information, expertise in health outreach, knowledge of local service resources, and ability to make referrals. The CBO must be able to identify individuals able to communicate about sensitive issues including cancer facts, insurance status, and fears of disease and disfigurement. CBOs most also overcome barriers including staff availability, turnover, competing program priorities, and funding. Agencies must also have the means to evaluate and improve their programmatic efforts, in order to be accountable for achieving public health targets.

Academic centers have the potential to bring unique resources to help community-based organizations succeed in health promotion. These centers have ready access to the latest technologies and concentrate expertise in program development and evaluation. Academic centers have research expertise to help organizations to define whether and how they want to fit in to a continuum of care and to provide necessary technical assistance for planning, program development, training, and evaluation. They also tend to have greater access to information about evidence-based practice, emerging information on risk factors and treatment strategies, and ability to draw on sources of research funding that are not available to most CBOs. Academic centers can also exercise greater flexibility in how staff are deployed, especially staff involved in extramural research.

In the case of breast cancer screening, academic medical centers receive support from the National Cancer Institute and other research sponsors to develop new screening methods, patient educational materials and the like. This sort of research may benefit individuals included in specific studies but these developmental studies generally in and of themselves do not reach entire populations. Indeed, there is a major concern that effective health promotion interventions are not widely disseminated and so do not impact standards of care (Gelijns & Thier, 2002; Kelly, Sogolow, & Neumann, 2000; Smith & Sutton, 1999). Although findings of research should translate back into the population health arena, there is no guarantee that innovations and expertise in screening reach the level of local mediating structures. Similarly, these local agencies rarely have direct input into the conduct and dissemination of relevant public health research.

With growing concerns about health disparities and inclusiveness in clinical research, centers have a clear obligation to find ways to fulfill their scientific, clinical, and academic missions through greater public service. Large academic medical centers are generally not themselves mediating structures in the sense that Berger and colleagues intend. However, academic medical centers may in fact serve a different kind of role by concentrating the latest findings and techniques of health-related research and forging multilateral partnerships with community-based organizations involved (or potentially involved) with public health initiatives to determine how to make best use of these resources in local communities.

## Perspectives on practice in partnership

We developed the ACCESS program to bring the special expertise and resources of our medical center directly to community-based organizations such as those involved in (or potentially involved in) the Health Women's Partnerships. At the same time, ACCESS was designed to learn from encounters with diverse communities to inform new program development and research efforts. Several perspectives on community practice and community organizing informed our approach (Hayden et al., 1997). The first involves partnership formation (Sebastian, Davis, & Chappell, 1998). Israel, Schulz, Parker, and Becker (1998) provide a key review of this concept. They emphasize partnership as a way of conceptualizing relationships between researchers and communities. The partnership model emphasizes collaboration to build knowledge and strengths of the researchers and the communities to help both partners achieve desired and often common goals. Barriers to partnership include lack of trust, difficulty communicating, competing demands, uneven power differentials, and limited funding (Nelson, Raskind-Hood, Galvin, Essien, & Levine, 1998; Schensul, 1999). In their recent review of the literature on partnerships, Roussos and Fawcett (2000) suggest key steps to partnership formation including action planning, developing leadership, feedback, and technical assistance.

A second perspective involves capacity building. This concept has been widely applied in areas ranging from international development (Kotellos, Amon, & Benazerga, 1998) to urban planning (Chavis, 1995). Capacity building introduces the possibility of expanding the autonomy and effectiveness of potential community collaborators by increasing their access to resources. Foster-Fishman, Berkowitz, Lounsbury, Jacobson, and Allen (2001) have identified collaborative capacity necessary for successful partnership in the following levels: (1) within their organization's members; (2) within their relationships (external); (3) within their organizational structure; and (4) within the program they sponsor.

A third practice perspective that informed the ACCESS project involves participatory action research (Arcury, O'Fallon, Tyson, & Dearry, 2000; Schulz, Krieger, & Galea, 2002). In participatory action research, researchers and community members collaborate on an on-going basis in an iterative process of problem definition, problem solving, and evaluation (Williams and Lykes, 2003) which may involve building research or programmatic skills, development of necessary tools, mobilization of new resources, and broadening and deepening relationships (Foster-Fishman et al., 2001). This model is particularly applicable to the problem of cancer-related health disparities which require sustained adherence to preventive health behavior and screening regimens, integrated pathways to care that may be readily accessed if and when needs arise, and adaptability in the face of emerging technologies and evolving recommendations for optimal self care.

A fourth key guiding concept involves sustainability. In order for community partners to use and sustain innovations in their programs, these new components must conform to the organization's culture and context. As Cohall (1999) and Cagan, Hubinsky, Goodman, Dietcher, and Cohen (2001) have noted, the biggest challenges for sustaining programs involves devising and revising methods to suit the changing needs of particular groups of women. Thus, Altman (1995) suggests that technology transfer or program diffusion must be viewed as a dynamic and bi-directional process. As a program or intervention for cancer screening is transferred into the field, it may be modified, perhaps significantly. Although changes may violate fidelity with the original design, such modification may be critical for the program to take hold. Several authors have tailored sustainable programs by identifying combinations of interventions to encourage screening or behavioral change (De Nooijer, Lechner, & DeVries, 2001; Gettleman & Winkleby, 2000; Lostao & Joiner, 2001; Stovall & Wright, 1998).

## Methods

This section of the paper focuses on the practice model that we developed to build relationships with community-based organizations in order to build their capacities to adapt, incorporate, and sustain breast cancer education and screening activities for their medically underserved constituents. It will be useful to summarize the early history of our program, to highlight key considerations that shaped our approach. We will then describe the major steps of our consultation and outreach model. As we shall discuss, the protocol for community outreach and partnership that we ultimately derived has been successfully introduced in numerous different settings and may lend itself to a wide range of public health concerns. In the "Results" section, we highlight the characteristics of the CBOs that we worked with and their clients and summarize an evaluation of the ACCESS Project, focusing on the extent of organizations' participation and the new breast cancer-related activities that they undertook.

### Evolution of the ACCESS model

The idea of ACCESS was and is to work with key personnel from CBOs to tailor programs suited to the particular constituencies that they serve and to identify resources needed to sustain these programs. However, we found it necessary to make a number of changes over the first two project years, prompted by our experiences implementing the program and feedback from participants. Our original plans gave way to an approach that was more responsive to community agencies' circumstances and needs.

Although most leaders of CBOs expressed interest in getting involved in cancer screening, we found that many practical factors interfered, including limited staff availability and turnover, funding, lack of experience in health-related areas, and competing priorities. Indeed, it was often the case that CBOs serving the most vulnerable groups faced the most barriers to participation. In order to avoid excluding these potential partners, we realized that we needed to develop ways to stay in touch with CBOs during lengthy periods of delays in implementing programs. We accomplished this by providing periodic cancer information updates and linking CBOs that were postponing their own programs to more active agencies in nearby neighborhoods. This helped us to stay connected with CBOs before they could commit to full-scale planning and program implementation.

We also found that many participants were interested in more in-depth program development and planning. This led us to combine separate parts of our program into a much more flexible training and consultation model geared to meet agencies' needs. We had originally anticipated that consultations would be time-limited. However this proved to be untenable. Stakeholders at many CBOs actually wanted to plan several distinct activities with ACCESS, tailored to specific subgroups of their constituents. Thus, we came to define our work with CBOs as open-ended; they could seek assistance from ACCESS to sustain or expand their cancer-related programs at any point after an initial consultation.

In terms of evaluation, we had originally planned to conduct several anonymous cross-sectional surveys of clients/constituents at each CBO before and after program implementation to detect changes in cancer awareness, perceived barriers to care, and screening behaviors. This proved to be problematic because some CBOs such as museums or street outreach programs have "audiences" that are very transient or only loosely connected to the CBO. Also, sampling repeated cross-sections could not detect effects of time-limited, cancer-related programs. For CBOs with distinct subgroups of clients, it was often impossible to know how to focus data collection until program planning was well underway. Ultimately, these difficulties led us to develop alternative evaluation strategies focused on setting activities. However, CBOs themselves were extremely interested in the data gathered on clients and members. These surveys which we relabeled "Community Barometers," were used as a needs assessment to help CBOs initiate program planning.

## Description of the ACCESS protocol for initiating and establishing partnerships

The lessons learned over the first two years of this project allowed us to make considerable refinements to ACCESS. We wrote a protocol for our staff to guide work with CBOs at every stage of the outreach, program planning, and implementation process. This manual is summarized in Table 1 which also shows the approximate sequence and timing of program milestones. This model is an important product of our work. It was developed to be used in many different situations with many different types of CBOs. It was designed as a process model that does not presume any specific approach or impose a specific intervention strategy. Rather, the idea is to ensure that CBOs and academic consultants follow steps to develop and sustain collaboration. We believe that this protocol may be useful to community health outreach efforts in a wide variety of circumstances. Key aspects of the ACCESS protocol are discussed below.

### *Recruitment*

As an outreach program, ACCESS used many channels to identify and recruit CBOs working with medically underserved women. CBO recruitment always involved a process of learning about a CBO's structure and leadership to determine the right level at which to engage the organization; to understand organizational roles and relationships involved in making program decisions and plans; and to identify the individuals who would work directly with ACCESS. This often involved several discussions with directors, program leaders, and board members. Ultimately, for CBOs that participated in our program, we completed a memorandum of understanding and a structured participant interview. In some ways, this memorandum was analogous to an "informed consent" between the ACCESS program and the CBO. It gave us the opportunity to explain the ACCESS program in depth, clarify expectations, and work out a projected timeline for the agency. It also provided an opportunity for us to assess necessary information about the CBO's resources and needs.

### *Engagement*

Many CBOs that were not able to commit to the program at the time we initially approached them, were none the less, interested in obtaining cancer information. This situation often required our staff to *ad lib*, doing everything from hanging up posters for health fairs, to meditation walks in a botanical garden, to discussions of women's wellness at harm reduction support groups. A residential psychiatric facility that we worked with had recently experienced deaths of two staff members due to breast cancer and asked us to lead several group sessions for staff around issues of bereavement and loss.

Although outside the formal parameters of the ACCESS program as originally envisioned, we came to realize that these activities were fundamental to forming partnerships and establishing a trusted identity in the community. Our willingness to deviate from a narrow agenda to join with CBOs in a manner that suited their immediate needs and concerns often did more to demonstrate the potential benefits of the ACCESS model than we could explain in our memorandum of understanding. Even CBOs that were ultimately unable to fully participate in the program came to see ACCESS as a valued resource and helped us to establish a positive reputation in the community.

### *Program enrollment and orientation*

ACCESS orientation was structured around a reception held monthly at our office. Several participants from two or three recently recruited CBOs were invited to the program which included luncheon or dinner. During orientation, program participants received an introduction to breast cancer and the importance of screening. Many participants particularly valued the opportunity to have their questions answered by a physician and this free-formed question and answer session about cancer became an important point of reference for many of the agencies with which we worked. Many participants had personal experiences with cancer while others were curious about recent news stories or controversies about cancer detection or prevention.

### *Setting readiness assessment*

During the process of recruitment, engagement, and enrollment, we gathered information about CBOs' readiness and capacities to undertake cancer-related programs. For planning purposes, setting readiness information was discussed in supervision and during case conferences to help our staff members anticipate issues and tailor program planning to each CBO. We have used data about CBO readiness and capacity to help us understand differences in CBOs' cancer-related activity (Rapkin, Jansky, & Massie, under review).

**Table 1** Process for facilitating partnership with CBOs

| Milestone/objective | ACCESS activity |
|---|---|
| Recruitment and initial entrée into CBO | ACCESS staff meet with key leaders and gatekeepers and identify CBO liaisons. May take one or several meetings. May include principal investigators (PI) and outreach staff |
| Engagement | ACCESS staff provides cancer information and referral with the intention of fostering a collaborative relationship with CBO. Outreach staff provide on-going, low-intensity assistance until CBO wants to progress |
| Program enrollment and orientation | Designated CBO liaisons attend a reception to learn more about cancer screening and to learn more about the ACCESS model. Receptions are held monthly for representatives from 2–3 CBOs and conducted by Pls and outreach staff |
| Setting readiness assessment | Using information gathered from multiple sources by outrearch staff, ACCESS presents a profile describing CBO's ability to sustain cancer-related programs |
| Community Barometer needs assessment and focus group | Outreach staff conduct interviews and focus groups with clients to assess women's needs, attitudes, and behaviors regarding cancer screening |
| Formation of CBO Planning Committee | Key people affiliated with the CBO are identified to participate in program planning process. ACCESS staff work with CBO liaisons and leaders to identify a planning committee |
| Program planning meetings | CBO's planning committee reviews their CBO's barometer results and setting readiness information. ACCESS staff help the committee identify potential problems and set goals, strategies and barriers to overcome |
| Media needs assessment, development, acquisition, and translation | CBO liaison(s) work with outreach staff to identify and review media materials from the ACCESS Media Resource Library |
| Consultation and resource development | CBOs receive assistance in grant writing, planning, needs assessment, board and staff development, and evaluation. Pls, investigators and fellows serve as consultants to the organization |
| Program implementation | Programs are tailored or 'fit' to CBO's culture and context. ACCESS staff observe programs as appropriate |
| Program review meetings | CBO Planning Committee meets to review implementation progress. Outreach staff use available data and problem solve with CBOs to help strengthen their efforts |
| Community Barometer readministration | Outreach staff administers the barometer to clients as a tool for post-program feedback to CBOs |
| Program modifications and redeployment | Program is revised and/or expanded as appropriate |
| Resource exchange | ACCESS facilitates (or CBOs self-initiate) connections among participating CBOs |
| Networking | ACCESS facilitates (or CBOs self-initiate) a meeting of multiple CBO representatives to prepare annual reports and/or quarterly updates |

### *Community barometer assessment*

Results of our Community Barometer surveys with CBO clients were provided to CBOs to foster discussion about cancer screening issues faced by the women they served (Lounsbury, Rapkin, Marini, Jansky, & Massie, 2006). This relatively brief instrument included sections on health service use and screening behavior, family history of breast cancer, perceived breast cancer risk, beliefs about breast cancer, and basic demographics. Procedures for obtaining data were flexible in terms of mode of administration and translation to accommodate different CBOs and clients. We have found that many CBOs wanted Barometer data for their own internal planning needs. This provided some CBOs with an incentive to get involved with ACCESS.

### *CBO planning committee meetings*

Our staff worked with our main participants from each CBO to identify in-house planning committees to discuss Community Barometer findings, brainstorm about program plans, and to assist with the implementation of cancer-related programs. Committee membership included CBO staff, volunteers and leaders, agency members or clients, local health professionals, and representatives from neighboring organizations. Committees have tended to be small and relatively informal. Committees met with ACCESS staff as needed to discuss ideas and develop plans. Although not a formal "advisory council," this mechanism helped to ensure that the breast cancer programs developed with ACCESS meshed with other agency priorities and concerns.

### *Media resource library and media needs assessment*

As CBOs' plans developed, they specified the educational material and training resources they required. We developed a comprehensive breast cancer "Media Resource Library" with over 960 items, including pamphlets, brochures, videotapes, breast models, shower cards, and other teaching aids. We obtained material in English, Spanish, and other languages when available. We also amassed professional and lay literature on breast cancer screening and treatment, barriers to care, health disparities, and community partnerships. In addition, we maintained an up-to-date list of professionals and breast cancer survivors willing to speak about their cancer experiences, resources for training women to perform breast self exam, cancer support groups, medical translation services, low-cost mammography facilities participating in the NYS DOH Partnerships, and mobile mammography services. In order to help CBOs use these information and training resources, we created a key-word searchable database with annotated entries for each item in the library and a media needs assessment form that allowed ACCESS staff to identify relevant material and CBO representatives to preview the materials to ensure that the information was appropriate for agency needs. This media library has been widely used by CBOs who have also contributed their ideas and materials.

### *Consultation for capacity building and resource development*

Consultation became an integral part of our activities to provide CBOs with flexible technical assistance needed to sustain breast cancer-related programs. Areas of our consultation included measurement development, needs assessment, staff training, grant writing, identification of referral resources, literature searchs, and outcome assessment. The expectation that we would have to maintain flexibility to help build capacity in response to CBOs priorities and needs proved to be a critical asset for our program. The potential to bring in needed skills and resources gave CBOs license to envision cancer-related programs that exceeded current expertise, resources, and staffing. Consultation also provided an excellent opportunity for post-doctoral fellows and other trainees at our institution to gain focal and circumscribed experience working in a hands-on role with community providers.

### *Program monitoring and implementation*

ACCESS staff did not participate in direct delivery of cancer-related programs or services to CBO clients. Rather, CBOs were encouraged to develop programs that they could conduct and sustain independently with resources that were already available or readily attainable. However, ACCESS staff members observed programs and events at CBOs to provide feedback and suggestions to participants.

### *Program review, community barometer re-administration, and redeployment*

After a CBO's program was implemented, ACCESS outreach staff met with CBO participants and planning committee members to review the results. Several agencies requested that we gather additional Community Barometers to get more detailed information about women's breast health needs and concerns. CBOs could make modifications to programs to make them as beneficial as possible. Program review and modification involved recycling through ACCESS program planning procedures until the CBO was satisfied that the program met client and agency needs.

### *Networking and sustainability*

We employed several strategies to promote sustained CBO involvement in cancer-related activities, including breast cancer updates, monthly announcements of women's health events in the New York area, a bi-annual ACCESS Bulletin, and periodic contacts with CBO participants. Once a CBO actually became sufficiently involved to plan a program with ACCESS, we found that the greatest threat to sustainability was staff turnover. A number of steps described above helped to sustain agency involvement, including training several participants from each CBO, developing the planning committee, and creating memoranda of understanding with agency leaders.

## Results

Results of program activities are summarized in a series of analyses including: (1) characteristics of CBOs served by ACCESS; (2) characteristics of CBO members/clients; (3) a summary of program outcomes at the setting level; (4) a process analysis that demonstrates the relationship of program outcomes to our training activity; and (5) examples of consultations to promote program sustainability.

### Characteristics of CBOs served by ACCESS

During the past two years, we have worked with 67 CBOs in various capacities. Of these, 28 (41.8%) of the CBOs that we worked with came to us through referrals from organizations that networked with other CBOs. This includes five (7.5%) from NYS DOH Partnerships, three (4.5%) from "First Saturday in October," a grassroots program that mobilizes the Latina community, and four (6.0%) from Bronx Health Link,

**Table 2** Categories of organizations that participated in ACCESS

| Description | % | *N* |
|---|---|---|
| Education/child development centers | 13.4 | 9 |
| Neighborhood associations | 11.9 | 8 |
| Breast health & cancer organizations | 10.4 | 7 |
| Hospitals/medical clinics | 10.4 | 7 |
| Faith-based institutions | 9.0 | 6 |
| Residential care units | 9.0 | 6 |
| Senior centers | 7.5 | 5 |
| Multi-service centers | 7.5 | 5 |
| Domestic violence organizations | 6.0 | 4 |
| HIV/AIDS care services | 4.5 | 3 |
| Substance abuse treatment centers | 3.0 | 2 |
| Immigrant services | 3.0 | 2 |
| Media | 1.5 | 1 |
| Employment services | 1.5 | 1 |
| Recreational facility | 1.5 | 1 |
| Total organizations | 100.0 | 67 |

an advocacy organization. An additional nine CBOs (13.4%) were referred to ACCESS by other umbrella organizations like the Chamber of Commerce, while another seven (10.4%) were referred by other CBOs already in our program.

In order to broaden our recruitment efforts, ACCESS outreach staff retrieved contact information from the web sites of all 57 Community Boards of NYC and asked the District Managers for lists of agencies that they would recommend for this program. Cold contacts through this source accounted for 15 of the CBOs in the program (22.4%). The outreach team also reviewed available Community Resource Guides and mailed invitation letters to appropriate CBOs. This yielded another 11 participants (16.4%). ACCESS outreach staff members brought in eight CBOs (11.9%) through their own networking and contacts. Another five CBOs (7.5%) were self-referred after seeing literature or stories about our program. Table 2 provides further information about the characteristics of all CBOs in our network.

## Characteristics of CBO members/clients

After recasting the Community Barometer as a needs-assessment tool, we obtained data from 23 CBOs (see Table 3). In order to characterize our sample, we will summarize Barometer data obtained from 842 women sampled across these 23 CBOs. Across CBOs, 70% of the women were Latina or African American, 42% were Medicaid recipients, 46% had not completed high school, and 51% were unemployed. Note that 41% of the women who completed the Barometer at these CBOs were over age 40. Eleven percent of these women reported having a first-degree relative with breast cancer and most women (86%) reported having had a physical in the past two years.

**Table 3** Characteristics of 842 women surveyed at 23 of the CBOs participating in ACCESS

| | % |
|---|---|
| Demographics | |
| Over 40 years old | 41 |
| African American | 21 |
| Latina | 49 |
| Graduated from high school | 54 |
| Currently employed | 49 |
| Live with spouse or partner | 37 |
| Receiving medicaid | 42 |
| Reported first degree relative who had breast cancer | 11 |
| Self-care practices | |
| Check-up by physician in the past 2 years | 86 |
| Prayer | 26 |
| Exercise | 30 |
| Diet | 19 |
| Herbal remedies | 26 |
| Screening behaviors | |
| Mammogram in past 2 years age >40 | 67 |
| Received clinical breast exam in the past 2 years | 73 |
| Check own breasts for breast cancer | 59 |
| Barriers to screening | |
| Pain | 8 |
| Time | 11 |
| Don't know where to go | 11 |
| Cost | 13 |
| Uncomfortable communicating with doctors about breast health | 22 |
| Afraid to perform breast self-exam | 22 |
| Knowledge and beliefs about breast cancer | |
| Recognized lump as a warning sign | 73 |
| Recognized nipple discharge as a warning sign | 28 |
| High worry about breast cancer | 37 |
| Higher likelihood of getting breast cancer than others | 15 |
| Few peers get regular mammograms age >40 | 41 |
| Breast cancer is less important than other problems | 27 |
| Most women with Brest Cancer lose their breasts | 55 |
| All ethnic groups have an equal chance of surviving | 71 |
| Almost every woman dies of breast cancer | 21 |

*Note*. $N = 842$ respondents from $N = 23$ organizations.

In terms of breast cancer screening, women in participating CBOS reported lower than average rates of recommended screening with 67% of women over age 40 and 74% of women over age 50 reporting having had mammograms within the past two years. Clinical breast exams in the past two years were reported by 73% of women while recent breast self-exam was reported by only 59%. Further, 63% of women mentioned at least one barrier that could interfere with screening including pain associated with mammograms (8%), lack of time (11%), not knowing where to go for care (11%), concerns about cost (13%), lack of comfort speaking to providers (22%), and fear related to breast self-examination (22%).

Women's knowledge and beliefs about breast cancer also raised some concerns. Although many women recognized breast lumps as a warning sign of cancer (73%), far fewer were aware of other signs such as nipple discharge (28%). Over a third of the women reported that they were very worried about getting breast cancer, over half felt that most women lost their breasts, and 21% believed that most breast cancer patients die of the disease. Nearly 41% of women over age 40 perceived that few of their peers obtained routine mammograms.

In order to better understand CBOs' level and pattern of cancer-related activity, we took several steps to quantify and group agency activity data. This analysis revealed four distinct patterns of results following participation in ACCESS, depicted in Fig. 1. The majority of CBOs (54%) primarily became involved in information and referral networks. Another group (16%) concentrated most on developing and providing informational programs. A third group (19%) undertook more comprehensive activities and programming, involving provision of information, networking, screening, and capacity building. Finally, a fourth group (10%) became heavily involved in multiple activities in one or more of these areas. These patterns provide a useful way to summarize the scope of activities that different CBOs pursued as a result of participation in ACCESS.

### CBO cancer-related activities and contact with ACCESS staff

Evaluation data provided information on ACCESS staff members' contact and involvement with CBOs up to the time of these analyses. Indicators include the number of ACCESS contacts with each CBO (range = 1 to 40), the number of ACCESS staff having contact with the CBO (range = 1 to 10), the number of staff who visited the CBO on-site (range = 0 to 6), and the number of CBO participants completing the full intake process (range = 0 to 3). As expected, patterns of cancer-related activities were associated with differences in contact with ACCESS staff. As might be anticipated, greater contact with our staff was associated with heavy and comprehensive patterns of cancer-related activity.

### Consultation for sustained cancer-related activity

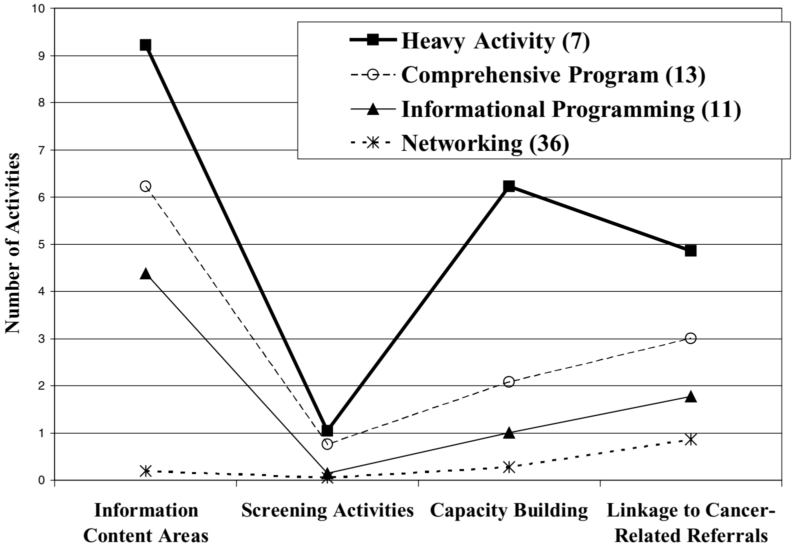
Two years after program completion, 76% of the CBOs that we worked with continue to contact us for up-to-date health information and referrals. Several CBOs that were not already involved (12%) joined the NYS DOH Partnerships (NYSDOH, 2002). Other participants (16%) formed partnerships with neighboring CBOs introduced in the ACCESS program. In a telephone survey of ACCESS participants from 18 different CBOs, we determined that 90% of respondents were interested in additional cycles of ACCESS consultation for planning new or expanded programs.

## Discussion

### Limitations and future directions

The direct correlation between the extent of ACCESS contact with CBOs and their level of involvement in breast health activities is not only evident in the outcome data; it was also apparent in our practical experiences in the field. As discussion of the evolution of the ACCESS model demonstrates, we have continued to enhance and refine our approach to community partnership development. As we

**Fig. 1** Program activity profile clusters ($N = 67$ CBOs)



gain more long-term experience with CBOs that have completed our program and others, we will continue to develop ways to promote sustained involvement in cancer-related activities. Specific plans for program enhancement include.

### *Broadening ACCESS training and outreach to address tobacco use, cervical and colorectal screening, along with breast cancer*

Our exclusive focus on breast cancer proved to limit some of what we could accomplish through the ACCESS Project. Target communities also experienced other cancer risks and delays in early detection. Many CBOs' participants asked for information about wellness and smoking and some materials in these areas have already been added to our media library. In addition to breast cancer, the NYS DOH Partnership has always funded low- or no-cost cervical cancer screening and recently began to support screening for colon cancer. This is particularly important because referrals to the Partnership ensure that medically underserved women can get access to screening and, if necessary, treatment. We suspect that broadening the spectrum of health issues we are able to address in ACCESS will strengthen our efforts in several ways. We will have: the means to engage a wider range of CBOs, more opportunities to tailor program content to meet CBOs' needs, and the ability to work with CBOs' to develop complementary and mutually reinforcing cancer-related activities.

### *Improving our ability to help CBOs tailor programs for clients by incorporating recent findings in the areas of cancer communications and message framing*

Up to this point, our approach to tailoring cancer-related activities and programs in ACCESS has focused on specific barriers and concerns identified by women, practical concerns of the CBO, and participants' judgments regarding clients' media preferences. Recent literature on health behavior suggests several other factors to take into account in tailoring programs. For example, Prochaska and DiClemente (1992) tailor messages according to individuals' readiness to change. Miller, Shoda, and Hurley (1996) focus on the individual's preference for more or less detailed information. Rothman and Salovey (1997) have focused on framing messages to maximize their impact. We plan to address these issues by revising our Community Barometer and adding focus group assessments. Armed with this information, CBO participants will work with ACCESS outreach staff to consider examples of cancer information messages, representing different combinations of gain-versus-loss, personal-versus-group, present-versus-future, and other salient attributes. This will permit a more comprehensive approach to media selection and program development, taking into account characteristics of participants and messages. Decisions to present more or less detailed information or to use gain-versus-loss framed messages will be made and tested at the local level.

### *Tracking health care use and cancer screening among women in CBOs participating in our program*

Ideally, evaluation should help us to determine whether or not CBOs' participation in ACCESS led to programs that helped clients/members make sustained positive changes in health behavior. One major limitation in our program concerned our inability to measure behavioral change at the individual level. Adding capacity to track behavioral change will be challenging because it represents a change in our relationship with CBOs. Originally, we ruled out the idea of enrolling and tracking individual women from CBOs. We were concerned that some CBOs would find the request to enroll members into a study so adverse that they would decline participation. Of course, this is still a potential concern. However, ACCESS now has a sufficient track record and identity in the community to refute the assumption that we are just another research project coming in to extract data from the community. Further, we have found that almost every CBO we have encountered is eager to obtain data that they can use for planning and documentation. Discussion with current CBO participants suggested that the opportunity to obtain summaries of quality data from ACCESS would be most welcome. Thus, we plan to obtain resources to allow us to conduct baseline and follow-up assessment for program evaluation.

## Conclusion

Through the ACCESS Project, we have attempted to put into practice concepts of partnership and community empowerment in a way that leads to systematic evaluation and replication. Experience with over 60 CBOs and preliminary evaluation results have demonstrated the feasibility of the model and have pointed the way to several program enhancements. As the public health community focuses more on overcoming health disparities and ensuring that advancements in cancer prevention, screening, and treatment reach all communities, we anticipate a growing interest in models to develop and sustain community-academic partnerships. We see such partnerships as a fundamental practice modality that involves special professional roles and requires a body of evidence to guide practice. Through the ACCESS program, we have had a unique opportunity to explore this area of practice and consider some of the approaches needed to make partnerships work.

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