

# The Cancer Information Service: Using CBPR in Building Community Capacity

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**Abstract** The National Cancer Institute's (NCI's) Cancer Information Service (CIS) Partnership Program followed many of the key principles of community-based participatory research in providing technical assistance to partner organizations. Using five case studies, this article describes how the CIS Partnership Program served to identify community needs and leaders, bringing resources together to build capacity and increase knowledge, and facilitate further dissemination of findings. CIS Partnership Program staff transcended the traditional health education role by building the capacity of community partners to bring cancer information in culturally appropriate ways to their own communities. The lessons learned by the CIS Partnership Program are useful for both academics and service organizations that would benefit from working with medically underserved communities.

**Keywords** Community-based participatory research · Cancer control · Cancer Information Service · Technical assistance · Capacity building · Medically underserved · Community partnership · Cultural competency

## Introduction

The National Cancer Institute's (NCI's) Cancer Information Service (CIS) Partnership Program aimed to increase cancer knowledge and awareness in medically underserved populations by working collaboratively with established national, state, and regional organizations with similar goals. A major role of the partnership program was to provide technical assistance and capacity building to partner organizations.

Although the CIS Partnership Program was a service program, the connection between CIS Partnership Program practitioners and the community in their work with medically underserved populations followed many of the key principles of community-based participatory research as outlined by Israel and her colleagues [1].

Through specific case studies, this article describes how the CIS Partnership Program incorporated the principles of community-based participatory research in developing the relationships necessary to provide technical assistance and capacity building. Although the contract supporting these national efforts ended in January 2010, the lessons learned by the CIS Partnership Program are useful for both academics and service organizations that would benefit from working with medically underserved communities.

## Literature Review

The National Cancer Institute established the CIS in 1975 as the premier resource for providing cancer information and

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education to the nation. The CIS reached the public through several communication technologies, including telephone service, e-mail, and instant messaging. From 2005 to 2010, there were 15 regional CIS offices covering the United States, the Virgin Islands, Puerto Rico, and several Pacific Islands [2]. All 15 regional offices operated a partnership program that worked with organizations to develop educational programs and interventions to reach underserved populations. Partnership program coordinators were located in every state. The partnership program collaborated with over 900 organizations and coalitions serving minority and medically underserved populations [3]. For example, 62% of CIS partner organizations served Hispanic or Latino populations, 86% black or African American and 68% medically underserved. Research activities were often integrated with regional offices, affording broader access to populations and expertise in planning, goal setting, and building capacity [4]. For innovative demonstration research projects, “The Digital Divide Pilot Projects” provide an example of how the CIS served as a resource to test new strategies for disseminating health information to vulnerable consumers [5]. This paper focuses on the service activities of the CIS Partnership Program, and how these activities, although not designed for research purposes, followed the principles recommended for community-based participatory research.

Community-based participatory research (CBPR) describes a process for creating knowledge and developing interventions achieved through partnerships between academia and community [6]. Historically, research followed a positivistic paradigm, which was believed to be an objective, neutral process for scientific discovery. Unfortunately, positivistic research failed to consider the influence of both the observer, and the observed on scientific investigation, discounting the subjective, cultural, and political features of building knowledge. CBPR serves to transform the researcher and subject into co-learners, whereby each of these research participants share power and bring their relative acumen and skills toward a comprehensive understanding of health and social phenomena.

One of the major tenants of CBPR research is that it is designed to address issues of interest to the community. This feature enables people to gain control over determinants of their health [7]. The selection of appropriate issues by the community provides inherent sanction, and allows community members to be fully engaged as research partners. Additionally, the issue-driven convocation of community empowers members to address the underlying social trauma that contributes to many health-related concerns, and that may be unapparent to external researchers [6].

CBPR is action-oriented. CBPR is conducted not merely to build an arbitrary body of knowledge, but for the purpose of identifying the determinants of community health that are amenable to change. CBPR provides the community with the requisite skills to mobilize to address health and social

challenges in a sustainable manner. Finally, CBPR engages the community in broadening the evidence base of effective intervention programs. The engagement of both academic and community research partners provides a better understanding of health determinants, and may extend the application of this new knowledge with comparable communities elsewhere [8].

Israel and colleagues describe eight basic principles of CBPR [1] (see Table 1).

The CIS Partnership Program utilized the principles of community-based participatory research in developing relationships in the community in order to provide technical assistance and capacity building. This article uses case studies to describe how the CIS Partnership Program incorporated those principles.

## Methods

All 15 CIS regional offices were asked to contribute partnership program projects illustrating the principles of community-based participatory research. The projects, submitted as examples, came from the offices of the paper authors. Case studies best illustrating the principles of community-based participatory research were selected by the authors.

## Results

Five case studies were selected. Table 2 summarizes the CBPR principles illustrated in each of the case studies.

**Table 1** Community-based participatory research principles (Israel and colleagues)

Principle	Description
Recognize community	Includes membership or geographical neighborhoods, and involves identification and emotional connection with other members
Build on strengths	Identify the resources and strengths that exist within communities
Facilitate collaboration	All parties participate as equal members
Integrate knowledge	Integrate knowledge into efforts to address concerns of the community
Promote co-learning	Facilitate the reciprocal transfer of knowledge, skills, capacity and power
Cyclical process	Include partnership development, problem identification and research methodology, and finally dissemination of results resulting in action taking
Address health	Emphasize physical well-being, as well as encompassing biomedical, social, economic, cultural, historical, and political factors as they impact health
Disseminate findings	Disseminate findings and knowledge gained to all partners involved

**Table 2** Community-based participatory research principles addressed by cancer information service

Principle	Clinical trial education	Body and Soul	Filipino collaborative	Food for thought	Comprehensive cancer control
Recognize community	x	x	x	x	x
Build on strengths	x	x	x	x	x
Facilitate collaboration	x	x	x	x	x
Integrate knowledge	x	x	x	x	x
Promote co-learning	x			x	
Cyclical process	x		x		
Address health		x	x	x	x
Disseminate findings	x	x	x	x	x

*x* is used to signify which of the eight principles are illustrated by each of the case studies listed across the top

Each case study demonstrates how CIS utilized multiple CBPR principles.

**Case Study: Clinical Trials Education Series Coalition Development in Hawaii**

The NCI developed the Clinical Trials Education Series (CTES) in 2001. CTES resources include a variety of materials including educational workbooks, brochures and pamphlets, and videos designed to increase awareness about clinical trials among public, patient, and health provider audiences.

In May 2002, the CIS Partnership Program (CIS Pacific) at the University of Hawaii Cancer Research Center (CRCH) interviewed cancer control stakeholders across the state to assess interest in and/or willingness to support clinical trials promotion/participation. These representatives were asked about their interest in promoting clinical trials and their willingness to serve on a clinical trial education committee.

During the project's introductory meeting, CIS Pacific staff presented the results of the initial stakeholder interviews, and an overview of the general barriers to and facilitators of clinical trials participation. In addition, CIS Pacific staff introduced the National Cancer Institute's Clinical Trials Education Series as a potential resource. Nominal group process methods were used to help the group brainstorm and identify additional local barriers to clinical trials participation, and possible methods to address these barriers. Participants were invited to become a member of the newly formed Hawaii Clinical Trials Education Initiative (CTEI). In 2004, the members of the CTEI chose to rename the group the Clinical Trials Education Coalition (CTEC).

The CTEC members considered and developed a sustainable plan for clinical trials promotion and education in Hawaii using CTES resources. The Coalition created specific committees to address goals relative to interests of each CTEC partner organization.

During the following 8 years, an array of projects were implemented, each project designed to build local aware-

ness of the importance of clinical trials in Hawaii. These projects ranged from the creation of media promoting cancer clinical trials to the public, to the introduction of clinical trials into the educational curricula of healthcare professionals, including medical and nursing students. Every project was developed through an ongoing collaboration among CTEC member organizations. The critical feature concerning the implementation of these projects was that they incorporated the CTES materials, using strategies determined by the local community members and stakeholders in cancer clinical trials.

This project used CBPR methods, including recognizing the community by engaging community stakeholders to disseminate the NCI's CTES resources. This enhanced the potential of these resources to reach broad segments of Hawaii's populations. Projects were developed that built upon the inherent strengths of partner organizations interested in promoting clinical trial research, allowing them to incorporate clinical trial promotion activities into their established organizational objectives. Finally, the Hawaii Clinical Trials Education Coalition and the projects implemented through this collaboration are durable and are expected to continue despite the closure of the CIS Partnership Program, nationally, and in Hawaii.

**Case Study: Body and Soul, the California Example**

Body and Soul is an evidence-based wellness program for African American churches, and was developed by the NCI and American Cancer Society (ACS). The program promotes nutrition, cancer prevention education, and other healthy lifestyle practices. The NCI Cancer Information Service served as a channel for Body and Soul dissemination through community partner organizations at the state, regional and local level. Community partner organizations recruited churches, trained and oriented churches to Body and Soul, and provided dissemination and implementation support and technical assistance.

The CIS California Region developed dissemination partnerships with the American Cancer Society—California

Division, California Department of Public Health's Network for a Healthy California—African American Campaign, and the University of California San Francisco Cancer Center Community Advisory Board's Faith Committee. The CIS role included conducting initial assessments to determine appropriate community partner organizations and areas for Body and Soul dissemination. CIS also planned, conducted and evaluated Body and Soul Community Partner trainings, and provided follow-up technical assistance for capacity building, program implementation and to advance evidence-based cancer control practice to reach minority and underserved African Americans.

Communities reached through this project were targeted based on geographic areas with high concentrations of the African American population, faith-based organizations, community partner organizations interested in reaching the African American community, and areas with low-income African Americans who meet United States Department of Agriculture Food Stamp program eligibility [9].

One of the key principles of Community-based Participatory Research outlines building on the strengths and resources within the community. In the African American community, the church is one of the most enduring and trusted institutions and is appropriate for health outreach due to its combined religious and social functions. The African American church also possesses characteristics and practices that support and foster the adoption of the Body and Soul health promotion effort [10]. Through the community partner organizations relationships with the churches, and CIS technical support, the California Region Partnerships for Body and Soul dissemination accomplished the following: (1) Leveraged resources of CIS, ACS and Network for Healthy California-African American Campaign to support training, dissemination, adoption and implementation of Body and Soul through 12 community partner trainings, 300 participants, resulting in 37 churches implementing Body and Soul. (2) Collaborated with UCSF to disseminate Body and Soul to churches, and train churches to use Body and Soul as a catalyst for developing or strengthening 17 church health ministries. Also, the project helped plan and convene two UCSF annual health symposiums on building and sustaining health ministries through evidence-based programming and reached 290 participants, representing 50 churches

### **Case Study: Filipino Community Cancer Collaborative**

The Filipino Community Cancer Collaborative (FCCC) is a multi-disciplinary coalition of community members, organizations, and stakeholders committed to improving the health of Filipinos in the Greater San Francisco Bay Area. Its mission is to empower the community through culturally responsive cancer related education, programs and services.

The CIS collaborated with FCCC on various levels: capacity building and coalition building as well as program planning, implementation, and evaluation. The CIS introduced evidence-based program planning to FCCC, and trained members on cancer health data related to Filipinos, which included use of NCI's Consumer Health Profiles and a specific example of an evidence-based cancer program intervention that reached Filipinos. The CIS facilitated the next step of identifying a mission, goal, and objectives for the group.

CIS facilitated three trainings on how to conduct a needs assessment, focus group and adaptation of an evidence-based cancer program intervention. A grassroots community assessment was implemented to evaluate Filipino access to cancer information, health communication preferences, and cancer topics that Filipinos were most interest in learning about. The assessment assisted with strategic planning and prioritizing cancer education topics.

One hundred six (106) community responses collected from community liaisons, indicated that the preferred health communication was through media and health marketing. The topics that the needs-assessment participants were most interested in learning about included breast, cervical, colorectal, and prostate cancer as well as early detection cancer screenings and reducing cancer risks.

Focus groups were conducted to identify effective breast health messaging targeting Filipino women. Fifteen (15) female participants were recruited by a community-based organization. The focus group found that messages needed to be: family oriented, use respectful Filipino terms, and be direct. This led to the formation of the Filipina Breast Health Project that engaged small print media health promotion with community cancer education classes. A Tagalog breast and cervical health education flipchart was tailored for workshops. Workshops conducted by California's breast/cervical early detection cancer screening program reached 51 medically under/uninsured and low-income women on the importance of breast/cervical cancer screening and available free services. Two breast cancer screening awareness posters were developed and distributed to over 100 local business, vendors, and service organizations that reach Filipinos. FCCC developed press releases that were published in Filipino newspapers regarding the Filipina Breast Health Project.

The Filipino Colorectal Cancer Screening Awareness Project, led by a national advocacy and capacity-building health program, provided education to the Filipino community and healthcare providers serving Filipinos. Three community education workshops reached 64 community members on the importance of early detection colorectal cancer screening. One workshop reached 29 nurses regarding colorectal cancer data, colorectal cancer screening, and effective health communication strategies with Filipino

patients. A Filipino newspaper published an article about FCCC efforts and colorectal cancer screening among Filipinos. Eight cancer education products were developed: bilingual colorectal cancer screening brochures in English–Tagalog and English–Ilocano, factsheets on colorectal cancer screening/prevention in English, Tagalog and Ilocano, as well as “Filipinos and Cancer Health Brief” in English, Tagalog and Ilocano.

The Filipino Cancer Health Promotion Mailers, an adapted evidence-based intervention, reached 200 Filipino households with cancer health information through postcard mailers. Three English–Tagalog mailers were developed on breast/cervical and colorectal early detection cancer screenings as well as recommendations for behaviors that reduce cancer risks.

This project illustrates the iterative and cyclical nature of multi-disciplinary partnership building, capacity-building activities, and program delivery, one of the principles of community-based participatory research. It has allowed the group to repeatedly leverage and benefit from the expertise, networking and existing resources of its partners and relationships. It also created a cycle of long-term fostering of relationship, communication and trust building. FCCC is working to develop the coalition infrastructure and leadership as well as address coalition dynamics and cultural nuances.

### Case Study: Food for Thought

This case study showcases the joint efforts between Cancer Information Service (CIS) and the Center for Transdisciplinary Research on Energetics and Cancer at USC to reduce cancer disparities by accelerating dissemination of critical scientific information to Promotores de Salud in Los Angeles (LA), California. The specific goal was to encourage Promotores to incorporate evidence on the relationship between obesity and cancer in their community-based prevention efforts for Latinos. The project convened a summit to highlight research findings on the link between nutrition, physical activity and cancer. The CIS role was as the liaison between research and community agencies to work in partnership to leverage resources and convene this summit. CIS also assisted in the planning, promotion, execution, and evaluation of the summit. The target population was Promotores de Salud; this group was chosen because of the experience of the lead agency in providing professional development to Promotores.

The summit was convened in April of 2007 with 119 participants, representing 38 key grassroots community health agencies in the LA area. The evaluation techniques utilized included: pre-post test, workshop satisfaction surveys, brief intercept interviews, and pledges. The

assessment was completed by 92 Promotores (77% response rate). Knowledge increased by 30% between the pre- and post-test. Additionally, 98% of participants responded favorably to dissemination intention (“do you feel that you are ready to spread this information out in the community”). Sixty seven percent of participants ( $n=62$ ) completed pledges to disseminate learned information to at least five families. As part of the evaluation we also conducted brief intercept interviews at the summit, where we learned that the summit brought needed resources for Promotores to deliver messages that are crucial in creating healthier communities and that there is clearly a demand for such conferences on a more frequent basis. Additionally, this effort involved the community partners in developing an abstract and poster to be presented at the National Latino Cancer Summit. Outcomes included a second funding opportunity to convene four summits throughout the state of California. The summits were organized in San Francisco, Inland Empire, Los Angeles, and San Diego.

Disseminating findings to community groups is one of the critical principles for community-based participatory research. This project demonstrated not only in the ability of the CIS to coordinate the dissemination of scientific information developed at the academic institution to community groups, but also the potential for the community group representatives to further disseminate the information at the grassroots level.

### Case Study: Comprehensive Cancer Control in Hawaii

The development and implementation of the Hawaii Cancer Plan is an example of using existing community strengths and collaborations to develop interventions on multiple levels that are designed to improve cancer control outcomes, one of the CBPR principles. The 2003 Hawaii Cancer Plan was developed by a coalition of cancer control stakeholders, the Hawaii Comprehensive Cancer Control Coalition. The CIS identified and brought together members of the coalition. The CIS also assisted in facilitating discussions to identify cancer plan approaches, which focused on the effects of cancer along a continuum that included cancer prevention, screening, treatment, and follow-up care. Additionally, crosscutting issues were identified to further address cancer control from the interpersonal, intrapersonal, cultural, political, and economic contexts.

The members of the Hawaii Comprehensive Cancer Control Coalition established collaborative workgroups which were instrumental in coordinating the current projects involving multiple stakeholders, and establishing new initiatives that could address gaps in Hawaii's cancer control efforts. The activities of the Hawaii Comprehensive Cancer Control Coalition's Early Detection workgroup was charged

with promoting the benefits of early detection for specific cancers for which there are appropriate and cost-effective population-based screening strategies. The challenge for this group was to identify collaborative health promotion messages about cancer screening for the general public that would not be adversarial to the organizational perspectives and positions on cancer screening of the entities represented by each of these individual workgroup members. With consensus building assistance from the CIS, the group adopted a strategy to promote a more generalized health promotion message about cancer screening that demonstrated the importance of detecting cancers early without contending or contradicting the specific messages about cancer screening of the workgroup members' affiliated organizations.

This project illustrates the CBPR principal of facilitating collaboration. The “Get Screened” campaign of the Hawaii Comprehensive Cancer Control Coalition's Early Detection workgroup was successful in utilizing a concerted message that promoted the positive aspects of cancer screening rather than emphasizing the differences in opinion among the partner organizations involved with the collaboration. This campaign was also able to demonstrate a consistent and shared message to the public, reducing potential confusion about cancer screening guidelines.

## Conclusions

In these five case studies, the CIS Partnership Program served to identify community needs and leaders, bringing resources together to build capacity and increase knowledge, and facilitate further dissemination of findings. CIS Partnership Program staff transcended the traditional health education role of direct presentations to the target audience, by building the capacity of community partners to bring cancer information in culturally appropriate ways to their own communities. The CIS “trained the trainers or leaders” who would then move forward in addressing cancer in ways relevant to their communities.

These projects demonstrated that CIS Partnership Program was able to develop projects utilizing the principles of community-based participatory research. The five case studies illustrate all eight principles developed by Israel and colleagues [1].

1. Recognizing the community as a unit of identity. Communities recognized by the CIS Partnership Program included: communities defined by ethnicity/race, geographical areas distinguished by culture/healthcare access/socioeconomic issues, and groups organized around topic areas.
2. Building on strengths and resources within the community. CIS brought together the skills and assets of

individuals, develops collaborations/coalitions, utilized mediating structures such as churches (Body and Soul) and other organizations where members come together, and supported existing social structures

3. Facilitating collaborative partnerships in all phases of assistance. CIS involved partners in the problem definition, planning, implementation, and follow-up. CIS brought in collaborators from outside the community with specific skills and resources to provide assistance.
4. Integrating knowledge and action for mutual benefit of all partners. The CIS disseminated the results of research in which the community was involved, and integrated research results with community change efforts.
5. Promoting co-learning and empowering process. CIS encouraged a reciprocal transfer of knowledge, skills, and capacity. CIS shared information and decision making, and supported members of the partnership. One example is capacity-building training.
6. Involving a cyclical and interactive process. The CIS cycle of projects included : partnership development and maintenance, community assessment, problem definition, determination of action, action taking, identification of lessons learned, and mechanisms for sustainability
7. Addressing health from both positive and ecological perspectives. The CIS primarily focused on the health model, which emphasizes well-being (cancer prevention and early detection). However, there were projects utilizing the ecological model, which encompasses biomedical, social, economic, cultural, historical, and political factors. These projects incorporated cultural competency trainings and brought in a variety of expertise.
8. Disseminating findings and knowledge gained to all partners. All of the CIS case studies disseminated findings, provided feedback, and used lessons learned to inform further action.

These results are limited by the fact that the CIS Partnership Program closed down January 14, 2010. The timeframe for submission of projects unfortunately coincided with the last 6 months of the CIS Partnership Program contracts from the National Cancer Institute. Offices were focused on completing existing work and enclosing down operations. All 15 regional CIS Partnership Program offices had multiple partnership program projects, many of which may have illustrated community-based participatory research principles, but only these five were submitted for this paper. These case studies, however, demonstrate the CIS Partnership Program's capacity to build reciprocal partnerships with communities and disseminate important health information.

## Implications for Readers

Service-based projects working with community partners can benefit from the principles of community-based participatory research. In fact, these principles can ensure good relationships between the community and the service provider, and improve the quality of the project. Critical steps in building sustainable, productive, and trusting relationships in the community include recognizing the role of the community in the process and building on its strengths, working to facilitate collaboration and integrating knowledge both from the community and the service side, promoting learning together, building relationships and projects as part of a cyclical process to address health and other community needs, and finally disseminating findings.

## References

1. Israel B, Schulz AJ, Parker EA, Becker AB (1998) Review of community-based research: assessing partnership approaches to improve health. *Annu Rev Public Health* 19:173–202
2. Bright M (2007) The National Cancer Institutes Cancer Information Service: a premier cancer information and education resource for the nation. *J Cancer Educ* 22(1):S2–S7
3. LaPorta M, Haygood H, Kornfeld J, Treiman K (2007) Partnership as a means for reaching special populations: evaluating the NCI's CIS partnership program. *J Cancer Educ* 22(1):S35–S40
4. Fleischer L, Kornfeld J, Davis S, Morra M, Squiers L (2007) The NCI's cancer information service's research continuum framework: integrating research into cancer education practice (1999–2004). *J Cancer Educ* 22(1):S41–S48
5. Kreps G, Gustafson D, Salovey P, Perocchia RS, Wilbright W, Bright MA, Muha C (2007) The NCI digital divide pilot projects: implications for cancer education. *J Cancer Educ* 22(1):S56–S60
6. Minkler M, Wallerstein N (eds) (2008) *Community-based participatory research for health, from process to outcomes*, 2nd edn. San Francisco, Wiley
7. Cargo M, Mercer SL (2008) The value and challenges of participatory research: strengthening its practice. *Annu Rev Public Health* 29:325–350
8. Leung M, Yen IH, Minkler M (2004) Community based participatory research: a promising approach for increasing epidemiology's relevance in the 21st century. *Int J Epidemiol* 33:499–506
9. *Unequal treatment*. 2003, Institute of Medicine: Washington DC
10. Goldman M, Roberson JT (2004) Churches, academic institutions, and public health: partnerships to eliminate health disparities. *NC Med J* 65(6):368–72