CALIFORNIA
Breast Cancer
Research Program

Transforming Research

An Evaluation of the Community Research Collaboration Awards

Updated March 2006

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This report describes an evaluation of the California Breast Cancer Research Program's Community-Initiated Research Collaboration Program, based on awards granted from 1998–1999. The purpose of the evaluation was to determine the outcomes of the research grants, and to assess the influence the collaboration had on breast cancer knowledge, programs, and policy, as well as on the research itself and the community and academic research partners who were involved. This report describes the goals, methods, and findings of the evaluation. Future reports will provide information on the characteristics of the collaborations, and the influence of these characteristics on the outcomes of the research.

Background

The California Breast Cancer Research Program (CBCRP) is the largest state-funded breast cancer research effort in the nation and the fourth largest breast cancer research program in the country. Our mission is to eliminate breast cancer by leading innovation in research, communication, and collaboration in the California scientific and lay communities. The CBCRP was founded in 1993, when breast cancer activists, scientists, clinicians, state legislators, and University of California officials collaborated to win passage in the state legislature of the California Breast Cancer Act. Funded primarily by a tax on tobacco products, the CBCRP has awarded more than $164 million for 672 research projects at 73 institutions throughout the state.

The CBCRP is administered by the University of California, Office of the President. The Breast Cancer Research Council, an advisory committee to the CBCRP, sets our overall objectives, strategies, vision, and research priorities. The council is made up of scientists and clinicians, as well as representatives from non-profit health organizations, private industry, and breast cancer survivor/advocacy groups.

The Community Research Collaboration (CRC) Awards, developed in 1996, bring women most affected by breast cancer together with experienced research scientists to study breast cancer-related issues that are of interest to both. These awards require a partnership between community-based organizations (such as breast cancer advocacy organizations, community clinics, organizations serving women with breast cancer, or organizations serving communities of women affected by the disease) and research scientists. The partnerships work together to identify the research question, develop the research plan, carry out the research, interpret the results, and disseminate information to scientists and the public. The CBCRP has invested over $8.5 million in 39 CRC projects between 1997 and 2005, 5% of our funding for breast cancer research.

Our first evaluation of our CRC Awards, “Community Research Collaboration Awards: Report on the Evaluation/Capacity Expansion Project,” in 2001, found that:

- Women most affected by breast cancer appeared to be empowered as full partners in the research process;
- Populations rarely included in research, such as ethnic and racial minority women and lesbians, were being included.

Our first evaluation also recommended that we conduct this second evaluation to find out more about the impact of our CRC Awards on the people who conducted the research, on the communities they serve, and on health services and policy. Future evaluations will examine the characteristics of the collaborations, and the influence of these characteristics on the outcomes of the research.

Goals & Expected Outcomes

The founding principle of the California Breast Cancer Research Program—to partner with the community in the detection, treatment, and eradication of breast cancer—is in some ways best exemplified by the CRC Awards program. The CBCRP funds community/researcher collaborations in order to close the gap between what researchers study and what communities are concerned about. This is especially important in California, where little is known about breast cancer's impact on the state's diverse communities. Involving women most affected by breast cancer in research studies can also lead to broader dissemination and use of the results.

The CBCRP CRC awards are based on a research process called Community-based Participatory Research. Community-based Participatory Research requires the collaboration of an identified community with an academic or trained researcher to answer questions of interest to the community. The purposes of the research are to inform the community, take some action, or create some change. It involves community-researcher collaboration at all levels of the research process.

While historically there has been little research evaluating the outcomes of Community-based Participatory Research, many have described its benefits. According to the National Institutes for Health (NIH), Community-based Participatory Research may improve the quality and impact of research by:

- More effectively focusing the research questions on health issues of greatest relevance to the communities at highest risk;
- Enhancing recruitment and retention efforts by increasing community buy-in and trust;
- Enhancing the reliability and validity of measurement instruments (particularly survey) through in-depth and honest feedback during pre-testing;
- Improving data collection through increased response rates and decreased social desirability response patterns;
- Increasing relevance of intervention approaches and thus likelihood for success;
- Targeting interventions to the identified needs of community members;
- Developing intervention strategies that incorporate community norms and values into scientifically valid approaches;
- Increasing accurate and culturally sensitive interpretation of findings;
- Facilitating more effective dissemination of research findings to impact public health and policy;
- Increasing the potential for translation of evidence-based research into sustainable community change that can be disseminated more broadly.

This evaluation considers the following four questions:

a. Did the CRC research increase knowledge about breast cancer in the community being researched, the scientific community, and the general public; and did the research impact policies, programs, and funding related to breast cancer?

b. Did using community-based participatory methods improve the quality of the research?

c. Did participating in CRC research positively impact the community organization research partner and members of the community?

d. Did participating in CRC research positively impact the academic research partner?

Methods

The evaluation was limited to CRC Full Awards granted in CBCRP award cycles IV–V (1998–1999) to capture information from completed grants only. Interviews were conducted with both academic and community principal investigators of these awards. To determine the impact on the community of participating in Community-based Participatory Research, the executive director or board president of the community organization was interviewed if the community principal investigator was no longer with the agency. If more than two people were identified in the grant report as co-principal investigators, they were all interviewed.

Seven research teams were included in this evaluation. At least one person representing the community organization and one academic researcher were interviewed for each project. Twelve of thirteen eligible individuals representing the community organizations were interviewed and all nine eligible academic researchers were interviewed. Teams were randomly assigned a team label, A through G, to protect confidentiality. A list of the seven projects, with the names and affiliations of the community and academic co-principal investigators, is provided in Appendix C.

Consent to participate in the study was obtained from all participants prior to conducting the study through a mailed letter and consent form, and again at the beginning of the interviews.

An interview protocol was developed from previous interviews used for other evaluation studies and from a literature review on Community-based Participatory Research. The interview questions were pilot tested and minor changes were made before implementation.

A trained interviewer conducted standardized open-ended interviews over the telephone with each of the eligible individuals. Each interview was taped and transcribed by an outside service. Both the interviewer and the evaluator compared the audio interview with the transcription to ensure accurate transcription. The evaluator analyzed text from the transcripts using a computer-assisted qualitative analysis program.

The evaluator developed a classification system to assign scores to each of the expected outcomes described below in Table 1. The scores ranged from 0, which reflected lack of successful outcomes, to a 1, 2, or 3 reflecting greater degrees of successful outcomes. For example, one valuable outcome of any research project is the number of publications that result. In this evaluation, teams that had a greater number of publications were awarded more points then teams with fewer publications. Total scores are reported in Figure 1, page 21.

TABLE 1 Outcomes and Indicators

Outcome I	
The CRC project improved knowledge, and impacted policy, programs, and funding related to breast cancer.	The general public was educated about this project or the research results through media reports. The scientific community was educated about this project or research results through peer-reviewed journal articles. Targeted communities were educated about this project or research results through community or scientific presentations. Health education programs or health services have been improved or institutionalized because of this project or the research results. Health policy or government programs were affected by this project or the research results. Funding for research or programs was increased because of this project or the research results.
Outcome II	
Participating in the CRC project positively impacted the quality of the research.	Recruitment and/or retention was improved The research methodology was improved. The research analysis was improved. The dissemination of research results was improved.
Outcome III	
Participating in the CRC project positively impacted the community organization partner and members of the	The community-based organization benefited from being involved in the research project. The question answered was important to the community. Community members benefited from participating in the research project. Community members increased their knowledge of breast cancer. The community-based organization is continuing to participate in Community-based Participatory Research projects.
Outcome IV	
Participating in the CRC project positively impacted the academic partner.	The academic researcher benefited personally or professionally by participating. The academic researcher is continuing to participate in Community-based Participatory Research projects. The academic researcher gained increased knowledge about the community and community interests.

Findings

Each of the projects added valuable knowledge about breast cancer in specific communities. Five of the seven projects arose from underserved populations who are under-represented in research. These populations include rural women, lesbians, Hmong women and men, women with disabilities, and Samoans.

The projects also addressed important questions about risk and causation, health education and service programs. Four of the projects developed and evaluated new programs or services to fill unmet needs; a fifth project compared academic and community models for delivery of support to women with breast cancer. Two projects explored breast cancer risk and causation among specific communities—lesbians and Marin County women. Descriptions of the projects and their research results are provided in Table 2, page 22.

A. Did the CRC Research Increase Knowledge, and Impact Policy, Programs, and Funding?

KNOWLEDGE

All seven teams reported presenting their data at scientific meetings. Six teams reported their data through the media, including two teams to national media. To date, 14 articles have been published in peer-reviewed scientific journals by four of the teams, or other researchers, and more articles have been submitted. See Appendix A for a list of published papers related to the projects included in this evaluation.

Four teams presented their data in community forums. Because the research teams included members of the community, the researchers were able to communicate on the communities' own terms. A research team member from a community-based organization serving a minority group commented,

> *When we went into the community, we had our research partners with us. But to ensure that the discussions were well understood, because many of our traditional leaders have difficulty in fully understanding terminology, then of course we took the lead in that.*

POLICY

All seven teams reported having some impact on policy or government agencies. The research teams leveraged access to policy makers by:

- Participating in meetings where they were able to discuss the study and study results;
- Organizing forums with local, state, and federal policy makers;
- Being invited to join committees;
- Being recognized as experts on the issue and therefore being contacted by policy makers;
- Working in coalition with other groups doing policy work.

The ways the CRC research projects had impact in the policy arena included:

- The issue one research team studied became visible to local, state, and federal policy makers and government agencies through meetings, publications, and other communications.
- Protocols developed in one project have been distributed throughout the country, including on federal websites.
- The intervention developed and evaluated by one research team has been used for local, state, and federal advocacy to increase access to breast cancer screening services.
- Another research project is credited with raising awareness among county, state, and federal public health officials about the issue being studied.
- Other community-based organizations use the information from

one project to advocate in the policy arena.

- One community-based organization involved in a CRC research project has engaged with state and federal policy makers regarding the programs their research evaluated and collaborative research in general.
- Other state and international governments have expressed interest in replicating an intervention that was studied by one research team.

HEALTH SERVICES OR EDUCATION PROGRAMS

All seven teams reported impact on health services or health education programs. The types of impact included:

- One community-based organization is more committed to outreach because it is more aware of the need for breast cancer screening in the population the team studied. Data is being re-analyzed to look at other diseases in this population.
- One community-based organization is more active in advocating for changes in services and increased visibility for breast cancer screening for the population the team studied.
- Conducting one study and reporting back at community forums educated providers, community members and other community-based organizations. Service providers in the area now include more information about this community in their programs.
- One community-based organization developed a new health education initiative in the county based on study results and is conducting further studies.
- An expanded network of providers now serves the community studied by one research team. More services now target the population the team studied.
- One community-based organization is more committed to its own program because it understands why the intervention works.
- Interest around the country and in at least one other country is very high to replicate an intervention developed and evaluated by one research team.

See Appendix B for a list of materials developed related to the projects included in this evaluation.

One community-based researcher from a CRC team commented on how the research brought more access to services to the communities the team studied:

> *I think that one of the things that has happened is that we have connected to resources in the area to where many of them [other community-based organizations] did not know how to outreach into our communities…*

LEVERAGING ADDITIONAL FUNDING

Six teams said that the results from their studies or their involvement in the research projects helped them to participate in or leverage ten additional breast cancer-related grants, totaling almost $20 million in additional funding. Three teams received four additional grants from the CBCRP for new or related studies totaling $1 million. Two teams received three direct grants totaling under $1 million for additional studies or projects in breast cancer from other funders. Most of the other grants included in the near-$20 million total are being conducted at multiple sites, and the CRC research team only receives a portion of the funding. One team credits the CRC study they conducted with spurring increased federal funding into research in their community:

> *There had been no federal money that came into [our community] to do research. And now, since 1997 I can do a whole timeline of things that have occurred in [our community] and I certainly would credit it with the beginning of [the organization] and certainly doing the [CRC study].*

B. Did Using Community-based Participatory Research Methods Improve the Quality of the Research?

RECRUITMENT AND RETENTION

Six of the seven teams said that recruitment and retention were positively impacted by the Community-based Participatory Research structure in significant ways. A common response from research teams was that they were able to recruit a large sample, and keep participants involved in the research, because the participants trusted the community-based organization. Community members also worked hard to recruit and retain participants. The collaborative structure of the research improved recruitment and retention in additional ways:

- Community involvement made it possible to find hidden populations and get a larger sample size.
- In one research project, community members were actively engaged in recruitment for the study from the community-based organization's own programs. The research team involved other employees of the organization, although this led to difficulty randomizing patients.
- Another research team reported "incredible success" recruiting participants from people already being served by the community-based organization.

One researcher commented,

> *I mean, out of 809 people that we recruited basically we lost two people in nine months, or three people in nine months. Come on. Tell me any other model that can help you get that low an attrition…And that was not because people refused. But people moved or died. And you can't have that by yourself without being connected with the community and the community being in the forefront.*

RESEARCH METHODS

Four of the seven teams reported that community involvement significantly improved the development of their research methods, in the following ways:

- People from the target community made the study more relevant;
- The research team was able to design the study knowing the reality of the community;
- The community brought sensitivity to aspects of the study, such as the informed consent process, that benefited the study design.

One team credits community involvement for designing a new research tool that is in use by other researchers.

DATA ANALYSIS

Most research teams did not collaboratively analyze their data, including those teams who collaborated well in other areas. Four teams found little or no benefit to the analysis of data through the collaborative structure. Two teams found minimal benefit and only one team found significant benefit. Two researchers stated that "data is data." A member of one team commented:

> *It was more the academic partners that were providing the leadership for the analysis part of it, whereas the community partners were providing their perspectives on what the potential inferences could be.*

The team that found the most significant benefit said that community involvement in the data analysis was essential. This was because hidden information about what was happening in the community during different parts of the study—which impacted data collection—would not have been known without community partnership in data analysis. As one member of this team pointed out,

> *The data doesn't mean anything unless you put the community into it [to add] the cultural variations to explain some of the things we were seeing.*

DISSEMINATION

The collaborative structure impacted dissemination of the study results in several ways. All teams reported that both the community partners and the research partners participated, on some level, in the dissemination of study results. Two teams found significant benefit to results dissemination using the community/researcher collaborative process. One of those teams paired widespread community dissemination with extensive scientific dissemination. Four of the teams found considerable benefit, but these teams focused mostly on either community-level or scientific dissemination, but not both. One of these four had minimal scientific dissemination and significant community-level dissemination but did not conduct these activities collaboratively. Finally, one team found collaborating had minimal impact on dissemination.

One member of a team explained how collaborating on research improved dissemination:

> *We wanted the results to be more than just data, but to have some living meaning for the women*

C. Did Participating in CRC Research Positively Impact the Community Organization Research Partner and Members of the Community?

BENEFITS TO COMMUNITY-BASED ORGANIZATIONS

Four community-based organizations identified significant benefits from participating in a CRC research project. These agencies became very active in Community-based Participatory Research projects, and their agencies received funding, visibility, and recognition for their work in breast cancer research. Others indicated that their agency received increased visibility or credibility for having participated, and that fundraising was enhanced.

One agency had been a very small organization with a small budget and was able to become more institutionalized because of the funding and the research project. This agency became known in their community for being committed to finding answers to breast cancer through Community-Based Participatory Research. Four community-based organizations or community members representing the organizations received an award or honor for their work on the research project.

Community-based organizations also cited additional benefits:

- Collaboration with other community-based organizations;
- Identification of community needs;
- Growth of the organization;
- Further use of data;
- Increased community understanding and support for research;
- Knowledge of which interventions work;
- Credibility for researching the agency's own programs;
- Empowerment of women involved in the research project.

IMPORTANCE TO THE COMMUNITY

All seven projects identified ways in which the research question was important to their community. One project attempted to answer a question that had received widespread media coverage as a "crisis" in that community. Another team thought that breast cancer was important to the community but the particular question they attempted to answer—which was developed through team discussions of feasibility as well as community importance—was probably less important to the community. One team reported that the research had empowered the community.

BENEFITS TO MEMBERS OF THE COMMUNITY

Individual community members also benefited from participating on the research team and as research subjects. Research team members reported that they gained greater research and evaluation skills, and greater knowledge of specific aspects of research, such as questionnaire development. Four studies paid research subjects a stipend for participating. Some of the benefits identified by community members who worked on the research team include:

- Increased computer, research, publication, public speaking, spokesperson, and survey design skills;
- Enhanced knowledge about Institutional Review Boards, which are committees of experts that ensure that research on humans protects the rights of participants;
- More knowledge about creativity in research and randomized trials;
- Increased medical literacy;
- Understanding of levels of risk and the “logic” of why research is conducted the way it is;
- Better understanding of media coverage of scientific research;
- Acquaintance with scientists;
- Ability to research the person’s own issues;
- The experience of working collaboratively with a university and academic partners;
- Increased understanding of how to turn a problem into a research question and of the differences between field vs. lab research, and qualitative vs. quantitative research;
- Knowledge about how to obtain funding to conduct research.

This increase in knowledge and skills has an ongoing effect for those who took part on the CRC research teams, as evidenced by this participant:

> *I feel, as well as all the community folks feel, that we're taken more seriously because we can speak the lingo. We've actually done research. We can go to any conference and we can present, so we feel we have a greater degree of respect for ourselves as well as at our agencies. And we're taken more seriously by funders, as well as policy makers. Because policy makers are like, "How do you know it works?" [And we say] "Well here, let me show you, here we have a journal article, and this and this and this." So it just really helped us to understand research and the importance of it and not to be afraid of it, as well as know research methods and how to do it and apply it in a community setting.*

INCREASED KNOWLEDGE ABOUT BREAST CANCER IN THE COMMUNITY

Four of the seven teams believed that conducting the study in their community, and reporting back to the community about the study results, significantly increased knowledge in the community about breast cancer. As one participant said,

> *There isn't a person in the community who doesn't know about the findings…It was on Nightline, it was on Sunday Morning. It was pretty amazing.*

Specific ways the research projects increased community knowledge about breast cancer include:

- Both disseminating the results and the conducting of the study was educational for one community.
- Members of another community participated in committee work for the research project.
- There were changes in behavior in one community.
- In another community, people know more in general about breast cancer and know it is a problem in the community.
- One community has become more aware about cancer, screening and risks.
- Another community is more aware of community initiated research collaboration. They understand the rigor required in conducting research.

CONTINUED PARTICIPATION IN COLLABORATIVE RESEARCH

Five of the agencies have continued to participate in Community-based Participatory Research. One would like to do so, but has not had a chance yet. In another team in which two separate agencies participated, one has continued participating in Community-based Participatory Research, and one has not.

D. Did Participating in CRC Research Positively Impact the Academic Research Partner?

PERSONAL AND PROFESSIONAL BENEFITS TO THE ACADEMIC RESEARCHER

Several academic researchers indicated that using Community-based Participatory Research led to their gaining credibility within the community they researched. They also had a positive experience meeting and working with the team, and had the opportunity to teach and give back to the community. Two researchers noted that they were able to leverage either a new position or additional staff at their universities with the project funds. One gained visibility and recognition, was invited to keynote a conference, was able to keep a research assistant, and was put under consideration for a full professorship. One researcher received an award that was in part a result of the work with the community.

All academic researchers identified some beneficial outcome, such as:

- Developed strong relationships;
- Got to know people, or a wider group of people, from the community being researched;
- Brought media attention to the issue;
- Gained experience doing collaborative research;
- Gained job security and professional experience;
- Met people for continued collaboration.

Academic researchers also made personal connections doing CRC research. As one commented,

> *I certainly [benefited] in the sense of meeting and becoming friends with really an extraordinary group of women. [This] collaboration has developed some very deep friendships.*

CONTINUED PARTICIPATION IN COLLABORATIVE RESEARCH

All but one of the academic researchers have continued participating in Community-based Participatory Research, either by developing new studies or participating in existing studies. One team's researchers felt "leery" of participating in another such project due to conflict among the team at the end of their study. Another researcher spoke of the time and energy commitment to conduct collaborative research and the inherent conflict for new researchers coming into the field:

> *I knew what it would take to get it done. I personally just tend to work at an extremely high level of energy. While this project was going on I also had 8 or 9 other projects going on. I came in with a lot of community connections and professional collaboration beforehand. That was able to carry me through for the publications that were required. And junior folks aren't going to have that, and that's why they suffer for it. And this is the primary piece—junior faculty of color. Because they've got the community connections, the communities are counting on them. And that's often why they go on for their degrees, to do research in their communities. And then they get caught in their obligations to the community versus their obligation academically to maintain their career. And that's why I think so few succeed.*

INCREASED KNOWLEDGE OF THE ACADEMIC RESEARCHER

Academic researchers gained increased knowledge of the community they studied. They reported gaining an improved understanding of what motivates community members to participate in research, more information about their culture or community values, and a better understanding of community needs and what services are useful. Researchers made the comments below regarding the knowledge they gained about the various communities where they conducted their research:

- The community is very interested in research on its issues.

- This community is complicated in terms of individuals' various identities and the ways they are and are not a community.
- I got validation that doesn't exist in the literature for what I already knew was the reality of the community.
- People who experience a disease are motivated to get answers about it.
- The community is open to help understand itself for betterment of society at large.
- Different people have different needs and they migrate toward the intervention that will work for them.
- The intervention developed in the research project was important to the population studied and there were differences within that population.

E. Combined Outcomes

All the outcomes studied were scored for their impact. Figure 1 is a graph showing the combined point totals for each team.

Of all outcomes considered, the areas where participating in CRC research had the most impact were:

- Recruitment/retention of study participants;
- Research methods development;
- Benefits to the participating community-based organization;
- The community having a question of interest answered.

Those areas where participating in CRC research had the least consistent impact include:

- Data analysis benefiting from Community-based Participatory Research;
- Leveraging additional funding for the research teams;
- Publishing articles;
- Community members receiving funding to participate as research subjects;
- The research team receiving an award or honor in recognition of their work.

All seven teams saw positive outcomes from participating in the CRC project. Three teams (C, D, and E) had the most positive outcomes. Their research results were presented to the general public, scientific audiences, and policy makers. Services were developed or improved and additional research has been embarked on. Collaboration made the research much better by improving recruitment/retention of participants and methods development. The communities benefited through increased visibility of the community-based organization and by getting answers to important questions. The researchers benefited through personal and professional relationships, continuing to participate in Community-based Participatory Research, and increasing their knowledge of the community.

Figure 1: Outcomes of CBPR

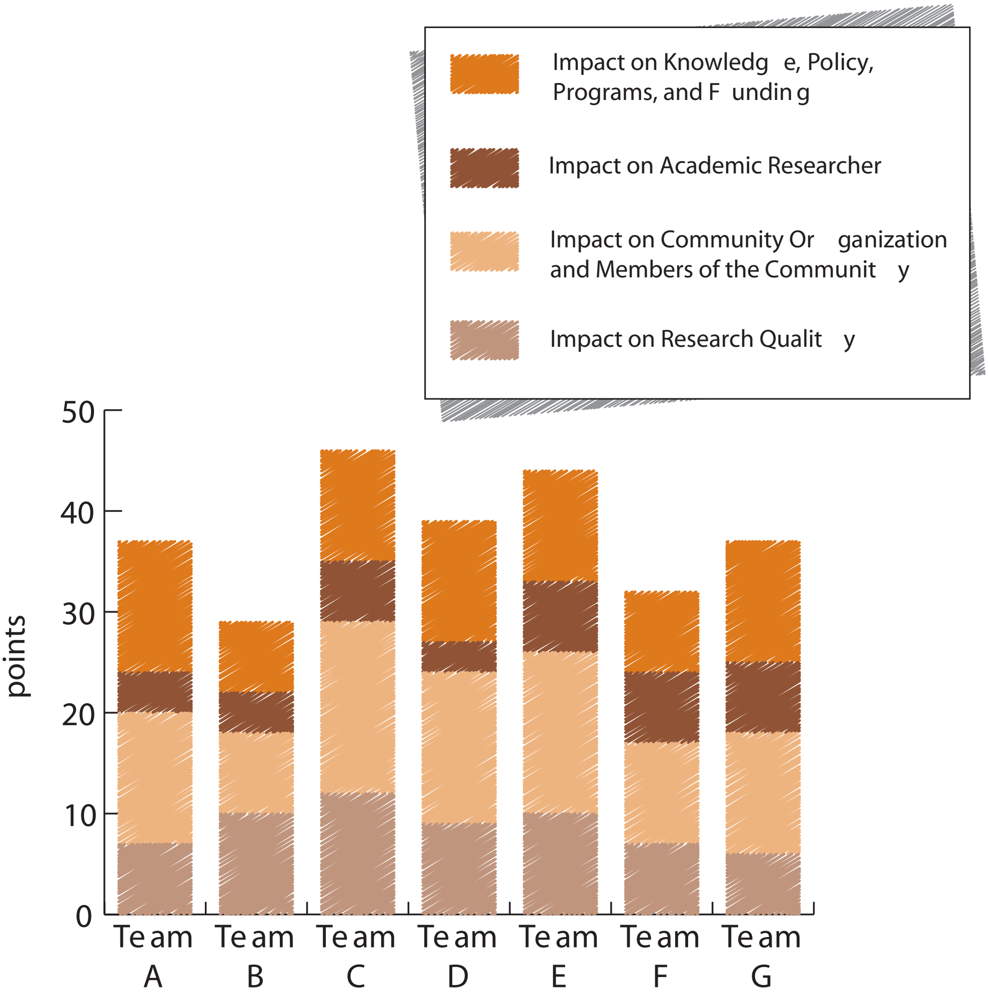

Table 2: CBCRP CRC Projects Study Results

A SUPPORT GROUP ALTERNATIVE FOR RURAL AND ISOLATED WOMEN

Rural and isolated women with breast cancer who received the One in Eight workbook-journal reported greater reductions in depression symptoms than did women who received typical care. Finding alternatives to face-to-face support groups is important for women who are geographically isolated. This research and intervention have widespread applicability to other women isolated by other situations or conditions, or who do not choose to attend support groups.

BREAST CANCER RISK FACTORS: LESBIAN AND HETEROSEXUAL WOMEN

The outcomes of previous research suggested that lesbians might face a risk for breast cancer two to three times higher than that of heterosexual women. In the CRC funded research, it was determined that lesbians indeed had a significantly higher lifetime risk for developing breast cancer (11.1%) when compared to their heterosexual sisters (10.4%). Accurate risk assessment of communities adds valuable information for outreach efforts both within and outside the community of interest and will encourage service providers, public policy makers, and funders to focus efforts on this population.

BREAST HEALTH PROJECT FOR HMONG WOMEN AND MEN

Breast cancer is the leading cancer death in Asian American and Pacific Islander women, yet these women have the lowest screening rates of all ethnic populations. A breast health education program was implemented to increase mammography rates among Hmong women. Hmong women are at greater risk for health problems due to language and cultural barriers, low education and poverty. The number of women who had heard of mammograms and obtained them during the study period nearly doubled after the health education program.

DO COMMUNITY CANCER SUPPORT GROUPS REDUCE PHYSIOLOGIC STRESS?

Previous research established that professionally-led support groups in a university setting benefited women with breast cancer. This study found that community support groups are just as effective. Women participating in community support groups saw changes in depression symptoms, trauma symptoms, social support, self-efficacy, and post-traumatic-growth, at about the same level over four months, as women in groups set in a university.

INCREASING BREAST HEALTH ACCESS FOR WOMEN WITH DISABILITIES

Regardless of how disability is defined (activities of daily living, instrumental activities of daily living, functional limitations, or having a mobility problem), the odds of a disabled woman being up-to-date with her mammograms decrease with the number of physical limitations she has. Findings from this research will reduce the human and economic impact of breast cancer for women with disabilities by filling an information void and by informing further research, policy initiatives, and the development of breast screening and education programs for women with disabilities.

MARIN COUNTY BREAST CANCER STUDY OF ADOLESCENT RISK FACTORS

Marin County has a high rate of breast cancer. This research project found that Marin women who drank at least two alcoholic drinks per day were more than twice as likely to be diagnosed with breast cancer as those who drank less. This research suggests that some risks even in this high risk population may be modifiable and that collaborative studies conducted in high breast cancer rate communities can provide insight into the causes of the disease.

SAMOANS AND BREAST CANCER: EVALUATING A THEORY-BASED PROGRAM

Samoan women were more likely to have ever had a mammogram if they had: positive group norms for obtaining a mammogram, health insurance, a belief that mammograms detect breast cancer, fewer misconceptions about the causes of breast cancer, fewer culture-specific beliefs about the causes of breast cancer, and higher self-efficacy. These findings could enhance breast cancer awareness, increase screening and early detection rates, and, over time, potentially lower the rates of illness and death from breast cancer in this marginalized community.

Note: Team codes A-G, used in Figure 1, were randomly assigned and do not necessarily correspond with the order of the list above.

Conclusions

The California Breast Cancer Research Program's Community Research Collaboration (CRC) Awards are a useful framework for meaningful inclusion of women most affected by breast cancer in the creation, implementation, and reporting of research on breast cancer. Each CRC project achieved high visibility within its community, significant distribution of its results, and impact in numerous areas—health education/services programs, policy advocacy, and increased scientific and community knowledge. The collaborative nature of the projects was cited by participants as adding important value to most of the steps in the research project. Therefore, our conclusions are:

1. Community-based Participatory Research is an effective way to stimulate research in populations under-represented in breast cancer research.
2. The CRC research projects funded by the California Breast Cancer Research Program (CBCRP) had positive outcomes in all the dimensions expected of Community-based Participatory Research projects: impact on knowledge, programs, and policies, impact on the quality of the research, impact on community agencies and members, and impact on academic researchers.
3. CRC Awards were most effective at improving the quality of research (especially recruitment/retention and methods development), at providing benefits to the participating community-based organization, and at taking on questions important to the communities involved.
4. For some teams, the CRC Awards were least effective at providing funding for community research subjects, leveraging additional funding for the research teams, impacting the analysis of data, impacting publishing of articles, and increasing researcher knowledge of the community.

Discussion

LIMITATIONS

This evaluation has several limitations. One limitation is the inability to weight the importance of different outcomes of the projects. For instance, if a team received a score of three for dissemination to the scientific community, and also received a score of three for dissemination to the targeted community, it is a value judgment to decide that those two forms of dissemination should be weighted equally. Perhaps community presentations should be weighted more greatly than scientific presentations in collaborative research.

Another limitation is that this evaluation focuses primarily on participants' perceptions, experiences, and views, and not on any external measures or validation. Finally, the evaluator did not consider whether the results of the research were important or statistically significant. Results that are not considered to be important in the field of breast cancer research or statistically significant can be expected to have fewer outcomes and little impact.

The limited number of projects (seven) included in this study and the qualitative research methods used limit the ability to generalize the results to other projects.

IMPLICATIONS

This evaluation provides evidence that the Community Research Collaboration Awards add significant value to the California Breast Cancer Research Program (CBCRP) research portfolio in many ways.

The majority of research we fund on populations under-represented in breast cancer research is funded through CRC Awards. Given the diversity of California, it is particularly critical for the CBCRP to stimulate research with these populations, and the CRC Program provides us an opportunity to do so.

In the past, research addressing underserved communities has often left community members feeling exploited by researchers who come in from outside and conduct research that leaves the community no lasting benefit. In contrast, the CRC Awards empowered communities to address questions that were important to them. The projects conducted through the CRC Program have brought significant benefit to the concerned communities and to individual community members. These projects have also had tangible impacts on community programs, policies and program funding. These results, and the collaborative methods used in the projects, have resulted in increased trust and appreciation of research in these communities. This may well increase trust and enthusiasm for research within these populations, thus stimulating further research.

The research methodology and results were improved through the collaborative process. Research conducted with funding from the CRC Awards had excellent recruitment and retention of subjects and developed culturally sensitive and community-tailored research methods. Interpretation of research results and dissemination of the results, especially to the general public and to policy-makers, were enhanced by the collaborative process. This allowed the research to move quickly to application in the real world.

This combination of findings strongly suggests that the CRC program may be the most appropriate and effective way to perform breast cancer research within California's diverse populations. The CRC Program provides the framework for more rigorous and relevant research within communities. This research empowers and benefits these communities and results in rapid translation and dissemination.

The projects studied in this evaluation did not consistently achieve all the outcomes expected of Community-based Participatory Research.. The significant variation in outcomes between projects and reasons for this variation should be more thoroughly explored. Since the outcomes were predicted based on the theory and practice of Community-based Participatory Research, and there is evidence from this evaluation that how Community-based Participatory Research was practiced by the CRC research teams varied, it is possible that variations in collaboration may explain all or part of the variation in outcomes. The lower impact of CRC research on analysis of data and publication of scientific articles are areas that should be further explored. Understanding the reasons for some teams not achieving these outcomes may allow for interventions that can increase these outcomes for future CRC teams. The CBCRP may be able to facilitate success in CRC Awards by providing education and technical assistance to teams, monitoring the practice of Community-based Participatory Research principles, and intervening as necessary.

The reasons that the CRC projects studied here did not achieve other outcomes expected of Community-based Participatory Research may be more heavily influenced by the external environment. CRC researchers receiving honors, awards, or funding to conduct additional research depends upon the extent to which Community-based Participatory Research is valued by others. Community-based Participatory Research is not yet universally recognized as scientifically rigorous or valuable to communities or academia. In the past five years, however, financial and other support for Community-based Participatory Research has increased. We hope this evaluation contributes to a better understanding of the benefits of supporting Community-based Participatory Research. It may be that an evaluation five to ten years from now would be much stronger in outcomes that depend on external recognition of the value of this type of research.

Finally, continued evaluation of our CRC Awards will allow the exploration of these and other questions, and increase the size of the sample as new projects are awarded annually.

Recommendations

Based on the results of this study, the CBCRP should:

1. Continue supporting, strengthening and possibly even expanding the CRC Awards.
2. Provide technical assistance to the CRC teams to ensure collaboration at all phases of the project, including data analysis and dissemination.
3. Prioritize the range of outcomes possible with Community-based Participatory Research and focus the CRC Awards Program to achieve those outcomes.
4. Explore the relationship between outcomes and how well Community-based Participatory Research was practiced by the CRC research teams.
5. Further explore reasons for the lower-ranking outcomes and consider interventions to increase these outcomes.
6. Continue to evaluate the CRC Awards and disseminate findings to larger audiences.

Acknowledgments

The authors of this study would like to thank the respondents who agreed to participate in the study and who took time from their busy schedules to consider their past experiences as a CBCRP CRC recipient. Thank you for your willingness to participate.

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Transcriber

Yvonne Day, Y. Day Designs
Graphic Design

Appendix A: Published Papers that Resulted from CRC Grants Included in this Evaluation

1. Angell, K., Kreshka, M.A., McCoy, R., Donnelly, P., Turner-Cobb, J., Graddy, K., Kraemer, H.C., Koopman, C. (2003) Psychosocial Intervention for Rural Women with Breast Cancer: The Sierra Stanford Partnership, *Journal of General Internal Medicine,* 18(7), 499–507
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5. Dibble, S, Roberts, SA, Nussey, B. (2004) Comparing Breast Cancer Risk between Lesbians and their Heterosexual Sisters. *Women's Health Issues* 14, 60–68
6. Hwang, E.S., Shiboski, C.T., Farren, G., Benz, C.C., Wrensch, M. (2005). Risk Factors for Estrogen Receptor-Positive Breast Cancer. *Archives of Surgery,* 140(1), 58–62
7. Kagawa-Singer M., Foo, MA, Tanjasiri SP et al. (Spring 2001) Breast Cancer Screening: Hmong Women in California. Breast Cancer Early Detection Program, *Los Angeles Journal of Cancer Education* 6 (1):50–4
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11. Tanjasiri SP, Kagawa-Singer M, Nguyen T-Y, Foo MA. (2004) Collaborative Research as an Essential Component for Addressing Cancer Disparities among Southeast Asian and Pacific Islander Women. *Ethnic Disparities* 14(3) Suppl. S14–9
12. Tanjasiri, SP, Kagawa-Singer, M, Foo, MA., et al. (In Press) Designing Culturally and Linguistically Appropriate Health Interventions: The "Life is Precious" Hmong Breast Cancer Study. *Health Education and Behavior*
13. Wrensch M, Chew T, Farren G, Barlow J, Belli F, Clarke C, Erdmann CA, Lee M, Moghadassi M, Peskin-Mentzer R, Quesenberry CP Jr, Souders-Mason V, Spence L, Suzuki M, Gould M. (2003) Risk Factors for Breast Cancer in a Population with High Incidence Rates. *Breast Cancer Research* 5(4):R, 88–102

Appendix B: Products and Materials that Resulted from CRC Grants Included in this Evaluation

1. Brochures (in English & Hmong) “Life is Precious” and “Lub Neej Yog Ib Yam Zoo Tshaj Plaws,” developed by Mari Nakamura.
2. Video (in Hmong with English subtitles) “Lub Neej Yog Ib Yam Zoo Tshaj Plaws: Kev Kuaj Mis Khees Xaws (Life is Precious: Breast Cancer Screening for Hmong Women), developed by Rod Lew.
3. “One in Eight: Women Speaking to Women. A Breast Cancer Workbook Journal,” developed by Mary Ann Kreshka and Illustrated and Designed by Kathy Graddy.
4. Memory Tools: Memory Board with Life Events Calendar, Visualization script with audio relaxation CD, and Photo montage, by Mary Gould, Georgie Farren, Flavia Belli, Roni Mentzer, Linda Spence and Margaret Wrench.
5. “Breast Health and Beyond for Women with Disabilities: A Provider’s Guide to the Examination and Screening of Women with Disabilities,” edited by Florita Maiki, Nancy Freed, et al.

Appendix C: List of CRC Teams Interviewed for this Evaluation

Note: Team codes A–G, used in Figure 1, were randomly assigned and do not necessarily correspond with the order of the list below.

Samoans and Cancer: Evaluation of a Culturally Appropriate Program

Pat Luce-Aoelua, National Office of Samoan Affairs, Community Principal Investigator

Shiraz Mishra, University of California, Irvine, Academic Principal Investigator

Breast Cancer Risk Factors: Lesbian and Heterosexual Women

Stephanie Roberts, Lyon Martin Women's Health Services, Community Principal Investigator

Doretha Williams-Flournoy, Lyon Martin Women's Health Services, Community Agency Executive Director

Suzanne Dibble, University of California, San Francisco, Academic Principal Investigator

Increasing Breast Health Access for Women With Disabilities

Carol D'Onofrio, Northern California Cancer Center, Academic Principal Investigator

Florita Maiki, Alta Bates Summit Medical Center, Program Manager

Ann Cuppolo, Breast Health Access for Women with Disabilities, Community Principal Investigator

Do Community Cancer Support Groups Reduce Physiologic Stress?

Mitch Golant, Wellness Community, Community Principal Investigator

David Spiegel, Stanford University, Academic Principal Investigator

Janine Giese-Davis, Stanford University, Academic Principal Investigator

Carol Kronenwetter, Cancer Support Community, Community Principal Investigator

Morton Lieberman, University of California, San Francisco, Researcher Consultant

Marin County Breast Cancer Study of Adolescent Risk Factors

Janice Barlow, Marin Breast Cancer Watch, Community Agency Executive Director

Margaret Wrensch, University of California, San Francisco, Academic Principal Investigator

Ronnie Mentzer, Marin Breast Cancer Watch, Community Research Team Member

Breast Health Project for Hmong Women and Men

Marjorie Kagawa-Singer, University of California, Los Angeles, Academic Principal Investigator

Mary Anne Foo, Orange County Asian & Pacific Islander Health Alliance, Community Principal Investigator

Mai Chew Chao, Community Outreach Worker, Community Principal Investigator

A Support Group Alternative for Rural and Isolated Women

Mary Anne Kreshka, Sierra Nevada Memorial Hospital Cancer Center, Community Principal Investigator

Cheryl Koopman, Stanford Health Center, Academic Principal Investigator

Distress, Coping, and Social Support Among Rural Women Recently Diagnosed with Primary Breast Cancer

Cheryl Koopman, PhD,* Karyn Angell,
Mary Anne Kreshka, MA,§ Patrici
Ayse Turkseven, BA,¶

Turner-Cobb, Ph
cca McCoy, LC
Davis, PhD,* a

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Breast Cancer Research Vol 5 No 4 Wrensch *et al.*

Open Access

Research article

Risk factors for breast cancer in a population with high incidence rates

Margaret Wrensch[1], Terri Chew[1], Georgianna Farren[2], Janice Barlow[2], Flavia Belli[2], Christina Clarke[3], Christine A Erdmann[4], Marion Lee[1], Michelle Moghadassi[1], Roni Peskin-Mentzer[2], Charles P Quesenberry Jr[5], Virginia Souders-Mason[2], Linda Spence[2], uzuki[1] and Mary Gould[2†]

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ed: 7 Apr 2003 Published: 29 Apr 2003

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nsive study of this or other areas of similarly
might reveal other important risk factors
gnosis.

cated immediately north of the city of San Fran-
veraged over the period 1995–99, age-adjusted
breast cancer rates per 100,000 white, non-His-
women were 199 in Marin County, 155 in the rest of
an Francisco Bay Area, and 144 in the United States
whole [2]. Pronounced international and national

OR = odds ratio; RDD = random digit

ELSEVIER

Women's Health Issues 14 (2004) 60–68

WOMEN'S HEALTH ISSUES

COMPARING BREAST CANCER RISK BETWEEN LESBIANS AND THEIR HETEROSEXUAL SISTERS

Suzanne L. Dibble, RN, DNSc[a*], Stephanie A. Roberts, MD[b], and Brenda Nussey, BA[a]

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Purpose. The purpose of this study was to explore the similarities and differences between lesbians and their heterosexual sisters in the established risks for developing breast cancer.

Methods. The design for this study was a matched (lesbian with heterosexual sister) cross-sectional, mail-back, anonymous survey. We distributed the surveys throughout the state of California to English-speaking women who identified themselves as lesbians, age 40 and older, and their sisters. Using the modified Gail Breast Cancer Risk model as well as other well-established factors associated with the development of breast cancer, we compared the breast cancer risk potential for 324 sister pairs ($N = 648$). Data were analyzed using paired t-tests, analysis of covariance (ANCOVA), McNemar's χ^2, or the Bowker statistic, as appropriate for the level of data.

Main Findings. The lesbians had significantly higher 5-year ($p < .0001$) and lifetime ($p = .001$) risk for developing breast cancer. The reasons for lesbians' predicted rate of breast cancer were most likely their higher scores on all pregnancy-related variables and the relatively high umber of breast biopsies they reported. The lesbians had used birth control pills less ($p <$ 001), had significantly fewer pregnancies ($p < .0001$), children ($p < .0001$), abortions ($p <$ 001), and miscarriages ($p < .0001$) as well as significantly more breast biopsies ($p = .02$) than d their heterosexual sisters.

nclusions. A lesbian who comes out to her clinician is relying on the clinician to be informed d be open to discuss her life. When a lesbian has a lump or a suspicious mammogram, she ds her clinician to advocate for her within the health care system because she is at higher for having cancer than a heterosexual woman.

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