CALIFORNIA
Breast Cancer
Research Program

Transforming Partnerships

The Relationship Between Collaboration and Outcomes in the Community Research Collaboration Awards

SEPTEMBER 2007

PREPARED FOR

California Breast Cancer Research Program
University of California—Office of the President
300 Lakeside Drive, 6th Floor
Oakland, CA 94612-3550
Toll-Free: 1-888-313-BCRP (2277)
Phone: (510) 987-9884
Fax: (510) 587-6325
E-mail: cbcrp@ucop.edu
www.cabreastcancer.org

INVESTIGATORS

Marj Plumb, Dr.P.H., M.N.A.
Community-based Participatory Research Consultant

Natalie Collins, M.S.W.
Outreach and Technical Assistance, Community Initiatives

Janna N. Cordeiro, M.P.H.
Coordinator of Special Projects

Mhel Kavanaugh-Lynch, M.D., M.P.H.
Director

Suggested Citation: Marj Plumb, Dr.P.H., M.N.A., Natalie Collins, M.S.W., Janna N. Cordeiro, M.P.H., & Mhel Kavanaugh-Lynch, M.D., M.P.H. (2007). *Transforming partnerships: the relationship between collaboration and outcomes in the community research collaboration awards.* Oakland, CA: California Breast Cancer Research Program.

CALIFORNIA
Breast Cancer
Research Program

Transforming Partnerships

The Relationship Between Collaboration and Outcomes in the Community Research Collaboration Awards

September 2007

Table of Contents

Introduction 1

Expected Project Outcomes and Partnership Characteristics 2

Evaluation Questions 3

Methods. 4

    Demographic Characteristics. 7

Findings. 8

    Breadth and Strength of the Outcomes of the CRC projects 8

    CRC Projects and the Principles of CBPR 10

        Levels of Collaboration 10

        Group Dynamics. 14

        Involvement of the Community Organization and Broader Community 18

    Overall Partnership Characteristics Scores 20

    Relationship Between Partnership Characteristics and Outcomes 21

Conclusions 24

Discussion. 25

Limitations 27

Recommendations. 28

References 30

Acknowledgments 30

Table of Contents (cont.)

APPENDICES

Appendix A:
CBCRP CRC Projects Study Results 31

Appendix B:
Peer Reviewed Articles and Abstracts that Resulted from CRC Grants in this Evaluation . .32

Appendix C:
Products and Materials from CRC Grants in this Evaluation 33

TABLE OF FIGURES

Figure 1:
Outcomes of CBPR 9

Figure 2:
Combined Partnership Characteristics 20

Figure 3:
CBPR Characteristics Compared to Outcomes 21

TABLE OF TABLES

Table 1:
Outcomes and Indicators Assessed 5

Table 2:
Partnership Characteristics and Indicators Assessed 6

Table 3:
Participant Demographics 7

Table 4:
Partnership Characteristics by Primary Area 10

Table 5:
Partnership Characteristics Differences Between High- and Low-Outcome Teams 23

This evaluation report describes the relationship between the strength of collaborations in the community/academic partnerships and the research outcomes from projects funded through the California Breast Cancer Research Program's Community Research Collaboration awards (CRC awards). It is based on an evaluation of awards granted from 1998-1999.The purpose of the evaluation was to determine the outcomes of the research grants and whether particular characteristics of partnership collaboration influenced the achievement of outcomes. The research outcomes were previously reported in more detail in "Transforming Research: An Evaluation of the Community Research Collaboration Awards," (2005), which is available online at www.cabreastcancer.org. The partnership characteristics, and the possible influence of these characteristics on the outcomes of the research, are reported here.

Introduction

The California Breast Cancer Research Program (CBCRP) is one of the top-rated breast cancer research programs in the United States. The mission of the CBCRP 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 $181 million for 761 grants at 92 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 nonprofit health organizations, private industry, and breast cancer survivor/advocacy groups.

The Community Research Collaboration (CRC) awards, developed in 1996, bring community members 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 members (such as breast cancer advocacy organizations, community clinics, organizations serving people with breast cancer, or organizations serving communities affected by the disease) and academically-trained 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 the scientific community and the public.

The CBCRP has invested over $14.2 million in 59 CRC projects between 1997 and 2007, representing 9 percent of the funds we have invested in breast cancer research. In 2001, a previous evaluation examined the processes we used to solicit applications and support these awards and found the program to be achieving the expected short-term outcomes. Among the findings were that those women most affected by breast cancer were empowered as full partners in the research process, and that research was conducted with populations not often included in research, such as ethnic and racial minority women, rural women, lesbians, and women with disabilities. A recommendation from that study was to conduct an evaluation to determine (1) the types of outcomes resulting from the CRC research projects; (2) whether participating in the CRC was beneficial to the participating community members, agencies, and academic scientists; and (3) whether knowledge generated from the research had any impact on health services or policy.

The 2001 evaluation also uncovered that some teams had difficulties achieving full collaboration throughout their study and that these challenges appeared to have impacted their projects. As a result, our subsequent 2005 evaluation was designed to evaluate the level and types of outcomes achieved by the CRC teams and to investigate if partnership characteristics had any influence on whether the teams achieved project outcomes. The outcomes were described in depth in a previous evaluation report, "Transforming Research: An Evaluation of the Community Research Collaboration Awards." They are also summarized in the Findings section of this evaluation report.

Expected Project Outcomes and Partnership Characteristics

The CBCRP funds community/academic 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. The CBCRP also sees the potential to increase dissemination and application of research results, because community members involved in research studies will be more likely to ensure broad 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, for the purposes of informing the community, taking some action, or creating some change.

While historically there has been little research evaluating the outcomes of community-based participatory research, many have described its benefits. For example, according to the National Institutes for Health (NIH), community-based participatory research has advantages that include:

- 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 surveys) 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.

Three Partnership Characteristics are considered especially important in community-based participatory research:

- Full collaboration and power sharing among partners are hallmarks of community-based participatory research. Full involvement of the community at each stage of the research process ensures that the research is relevant to and used by the communities most impacted (Fadem et al., 2003; Israel, Schulz, Parker, & Becker, 1998).
- Healthy group dynamics can lead to a positive working experience. This supports effectively minimizing (or successfully coping with) community organization staff or research team turnover, budget crises, and other instability that could negatively impact the partners' ability to collaborate fully and effectively on conducting the research (Goldstein, Freedman, Richards, & Grinstead, 2000; Maselli, Lys, & Schmid, 2004). Participants must also have the skills to engage in thoughtful self-awareness and self-critique, especially given the inherent power differences between most community members and their academically-trained partners (Marincowitz, 2003). Therefore, collaborative research requires an analysis and awareness of the power and authority of all partners. These power analyses should consider the partners' relative positions in society, knowledge of research methods, and access to research participants (Hagey, 1997).
- Broader community involvement includes involvement from grassroots community members and various levels of the sponsoring community-based organization, especially senior management, line staff, and the board of directors. Greater community organization involvement can ensure that a broader level of organizational support will be achieved. More comprehensive organizational support can lead to a greater commitment of organizational resources and effort, as well as more successful management of any turnover. Participation of community members from outside of the organization's staff can ensure that the project is representative of the community, not just of the few individuals included on the research team (Cornwall & Jewkes, 1995; Hatch, Moss, Saran, Presley-Cantrell, & Mallory, 1993; Lantz, Viruell-Fuentes, Israel, Softley, & Guzman, 2001).

Evaluation Questions

This evaluation report considers the following three questions:

a. What were the breadth and strength of the outcomes of the CRC awards?

b. Have the CRC projects been implemented according to the principles of community-based participatory research?

c. What is the relationship between characteristics of the research partnerships and the outcomes of the research conducted by those partnerships?

Methods

The evaluation on which this report is based was limited to CRC full awards granted in CBCRP award cycles IV-V (1998-1999), in order to capture information from completed grants only. Interviews were conducted with both academic and community principal investigators of these awards. In addition, in order 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 organization. If more than two people were identified in the grant report as principal investigators, they were all interviewed.

Seven teams were included in the 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 and all nine eligible academically-trained scientists 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 those participating in this evaluation is provided in Appendix D.

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 at the CBCRP and from a literature review on community-based participatory research. The questions covered the impact and outcome of community-based participatory research on the community, the academic scientists, and the research itself. Also covered were the facilitating and limiting partnership characteristics that led to positive or negative outcomes. 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 eligible individual. 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 accuracy. 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 and partnership characteristics described below in Tables 1 and 2. The scores ranged from 0 (reflecting no evidence of the outcome or characteristic), to a 1, 2, or 3 (reflecting greater degrees of evidence of the outcome or characteristic). For example, one valuable outcome of any research project is the number of publications that result. In this evaluation, teams with more publications were awarded more points than teams with fewer publications.

Four areas of potential outcomes were assessed, with each area including sub-areas of four to seven elements, as seen in Table 1 below.

Table 1: Outcomes and Indicators Assessed

OUTCOMES	INDICATOR
OUTCOME I	
The CRC project improved knowledge, programs, and policies related to breast cancer.	Health education programs or health services have been improved or institutionalized because of this project or the research results.
	Funding for research or programs was increased because of this project or the research results.
	Health policy or government programs were affected by this project or the research results.
	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.
OUTCOME II	
Participating in the CRC project positively impacted the quality of the research	The research question was improved.
	The research methodology was improved.
	Recruitment and/or retention were improved.
	The research analysis was improved.
	The dissemination of research results was improved.
OUTCOME III	
Participating in the CRC project positively impacted the participating community organization and members of the community.	The community-based organization benefited from being involved in the research project.
	Community members gained evaluation and research skills.
	The question answered was important to the community.
	Community members increased their knowledge of breast cancer.
	Community members or organizations received funding to participate in the research project.
	Community members are continuing to participate in collaborative research projects.
	Community members or the community organization received awards or honors for participating in the project.
OUTCOME IV	
Participating in the CRC project positively impacted the academic partner(s).	The academic partner(s) benefited personally or professionally by participating.
	The academic partner(s) gained increased knowledge about the community and community interests.
	The academic partner(s) continue to take part in community-based participatory research projects.
	The academic partner(s) received awards or honors for participating in the project.

Three areas of partnership characteristics were assessed, with each area including sub-areas of three to five elements, as seen in Table 2 below.

Table 2: Partnership Characteristics and Indicators Assessed

PARTNERSHIP CHARACTERISTICS	INDICATORS
PARTNERSHIP VARIABLE I	
Collaboration and power sharing by partnerss	The research question originated from the community.
	Each partner was involved throughout the research project from question development to developing the study methods, conducting the study, analyzing the data, and disseminating the results.
	There was an equitable balance in working together.
PARTNERSHIP VARIABLE II	
Healthy group dynamics of team	Team members had a positive experience working on the project.
	The team had few challenges in working together or conducting the study, or they successfully resolved any challenges they faced.
	There was little or no turnover of project personnel, or if there was turnover, they dealt with it easily.
	Team members had open and frequent interaction, information sharing, and discussion by both partners.
	The team had a written partnership agreement that included dealing with conflict and ownership of data.
PARTNERSHIP VARIABLE III	
Involvement of broader community and community organization	Community members outside of the community-based organization became involved in the project.
	Staff and board members of the community organization received regular updates about the research project and had the opportunity to participate in the project.

DEMOGRAPHIC CHARACTERISTICS

As seen in Table 3 below, academic partners reported having been involved in breast cancer for twice as long as community partners. Academic partners were also more likely to be white and to have had previous collaborative research experience. Four academic partners have or had tenure, four were in non-tenure-track positions, and one was a non-tenure-track junior researcher. Nine of the community partners reported having at least a master's level education. All seven teams reported having at least one community member with at least a master's-level education, with four teams having at least one community member with an M.D. and/or Ph.D.

Table 3: Participant Demographics

PARTICIPANT DEMOGRAPHICS	COMMUNITY PARTNERS (n=12)	ACADEMIC PARTNERS (n=9)
Average number of years involved in breast cancer [Range of years in breast cancer]	6 [0 to 20]	11 [0 to 30]
Average number of years involved in nonprofit organizations [Range of years in nonprofits]	13 [0 to 25]	
Average number of years identified as a researcher [Range of years as researcher]		16 [13 to 42]
Number of racial/ethnic minorities	5	2
Number with previous collaborative research experience	7	8
Number with masters degree or higher	9	9
Number with tenure		4

Among the seven teams, one reported having an academic partner with no collaborative research experience, one had an academic partner with minimal collaborative research experience, and the other five teams had at least one academic partner with extensive collaborative research experience.

Of the seven teams, two had community partners with no previous collaborative research experience, three had community partners with minimal to some collaborative research experience, and only two teams had community partners with extensive collaborative research experience.

In two of the seven teams, both the community and academic partners had none to minimal past experience with community-based participatory research.

Findings

BREADTH AND STRENGTH OF THE OUTCOMES OF THE CRC PROJECTS

As described in our previous evaluation report (Transforming Research, 2005), the CRC awards facilitate meaningful inclusion of those most affected by breast cancer in the creation, implementation, and reporting of research on the disease. Each CRC project achieved impact in numerous areas, including health education/service programs, policy advocacy, the increasing of scientific and community knowledge, high visibility within the community, and significant distribution of results. Collaboration was cited by most participants as adding important value to most of the steps in the research project.

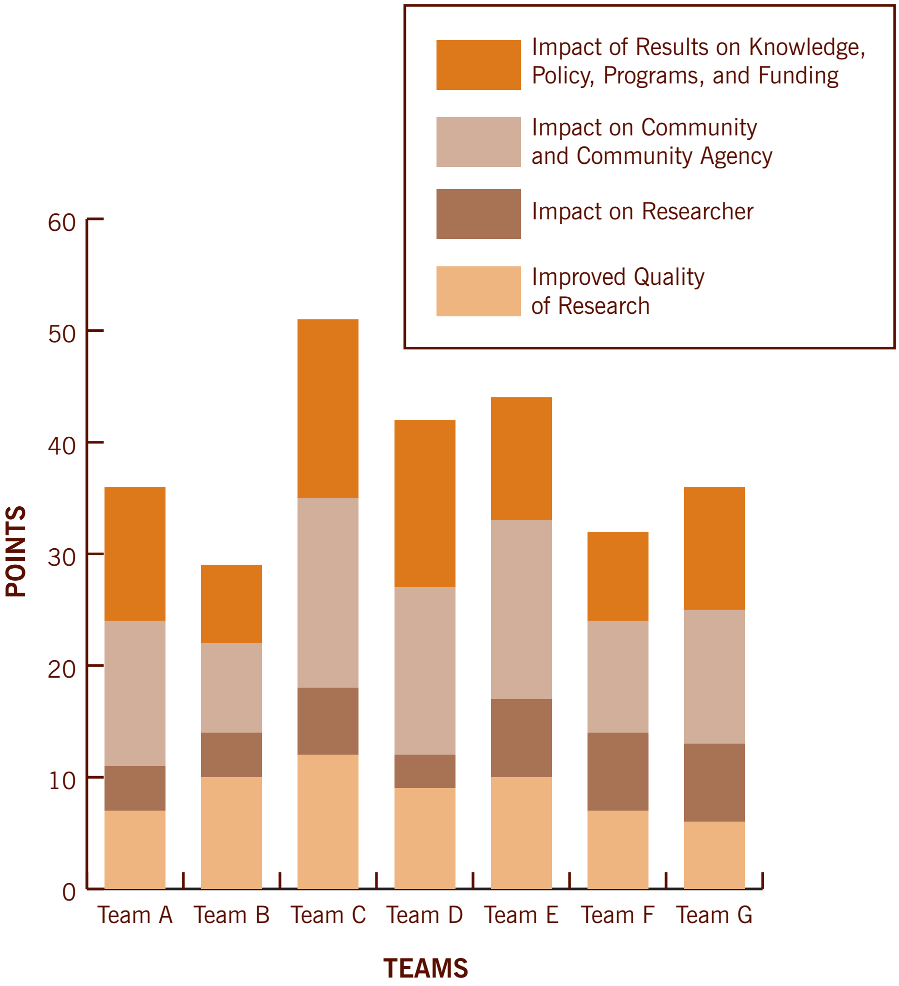
The conclusions, as reported in our previous evaluation report (Transforming Research, 2005), are:

1. Community-based participatory research is an effective way to stimulate research in under-represented populations.
2. The CRC research projects funded by the CBCRP all resulted in some level of positive outcomes in all four of 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 the research (especially recruitment/retention and methods development);
   - Providing benefits to participating community-based organizations;
   - Addressing questions important to the community.
4. CRC awards were least effective at:
   - Providing funding for community members to participate in the study;
   - Leveraging additional funding for the research teams;
   - Impacting the analysis of the data;
   - Publishing peer-reviewed journal articles;
   - Increasing academic partners' knowledge of the community.

(Note: Some teams have anecdotally reported greater success in these, as well as other dimensions, since the evaluation was completed).

Figure 1 shows the scores in the four outcome areas considered for all seven teams included in the study. Teams C, D, and E scored highest for the combined totals of all four outcome areas.

Figure 1: Outcomes of CBPR



Project results, peer-reviewed journal articles, and other materials developed through these CRC projects can be see in Appendices A, B, and C.

CRC PROJECTS AND THE PRINCIPLES OF CBPR

This study evaluated the question, “Have the CRC projects been implemented according to the principles of community-based participatory research?” by considering three primary areas: the levels of collaboration throughout the study period, the group dynamics in conducting the study, and the levels of involvement of the broader community and the participating community-based organization. Table 4 shows the average partnership characteristics score, within each of these three primary areas, for all teams, in order from high (3) to low (0).

Table 4: Partnership Characteristics by Primary Area

PARTNERSHIP CHARACTERISTICS	AVERAGE (n=7)	RANKING AMONG CHARACTERISTICS
COLLABORATION ELEMENTS		
Research question from community	2.29	1
Shared conducting study	2.14	2
Shared question development	2.00	3
Shared dissemination	2.00	3
Shared methods planning	1.57	4
Shared analysis of data	1.43	5
Shared power throughout project	1.43	5
GROUP DYNAMICS		
Level of communication	2.29	1
Relationship with partner(s)	2.14	2
Management of challenges in study	2.14	2
Management of turnover disruption	1.57	3
Written guidelines	1.29	4
COMMUNITY INVOLVEMENT		
Board/staff involvement	1.57	1
Broader community involvement	1.57	1

Each of the elements in the table above is explored in depth below.

Levels of Collaboration

Participants were asked to discuss:

- How the project came together;
- Whether the research question came from the community;
- Each member of the partnership’s involvement in selecting the research question, developing the methods used in the study, conducting the study, and disseminating the results; and
- The balance of power throughout the entire research project.

ORIGIN OF RESEARCH QUESTION: In five of the seven teams, the research question and the activities to create the partnership clearly came from the community or community organization, who sought out the academic partner to participate in the study. The academic partner in one team had seen the request for proposals from the CBCRP and approached the community partner. Another team was formed when a community member asked a health provider about breast cancer screening information that the provider did not know. The provider called a meeting of providers, researchers, and community advocates to discuss the question and from that meeting, the research team was formed. As one participant commented:

* * *

This was truly, and I'm very proud of it, truly a community initiated project.

* * *

DEVELOPING THE RESEARCH QUESTION: Teams developed research questions in different ways ranging from the academic partner developing the research question with input from the community principal investigator, to the academic partner acting as a consultant to a team of community members who then did "a tremendous amount of research to see what was going on in terms of epidemiology studies for breast cancer." The latter team met with experts, read articles, discussed the findings, considered the financial and research limitations, and decided what to study. Another team worked collaboratively throughout this step "at the kitchen table" in the academic partner's home. One member of this team described the process as "creative and synergistic." Another community partner commented,

* * *

We really focused largely on what were the important questions for the women with breast cancer that we were working with. So we worked collaboratively to look at what questions we were concerned about, and then our academic partners would really help us look at some of the literature and where the literature was going in terms of areas of interest.

* * *

DEVELOPING RESEARCH METHODS: Only two teams included the community partners equally in developing the research methods for their studies: the team mentioned above, which worked on each step at a member's kitchen table, and a team who utilized, at least in the beginning, their academic partner in a consultative role. In the other five teams, the academic partner drafted a methodology on his/her own and then solicited feedback from the community partner(s). One community partner commented:

* * *

We were all involved in [developing research methods] pretty much. There were some portions of it that were just decided without the community partners. But we were 60 percent involved.

* * *

CONDUCTING THE PROJECT: Three teams conducted the study in a fully collaborative style with both partners sharing equally in the work effort, the ongoing discussions and modifications, and facilitating the projects' conduct and completion. For two teams, the community organizations conducted the interventions, but did not experience a "feeling" of collaboration in the research. These groups described the process as more solo work than joint work with the researcher. One team "split the state" between the community and researcher principal investigators, with each doing their own work in different regions of California and coming together to discuss how it was going. The last team decided the community principal investigator shouldn't be involved in the actual study because she had developed the intervention and they were concerned about the appearance of researcher bias. One academic partner commented:

* * *

I was involved to the extent of making sure everyone felt comfortable with what they were doing. I trained some of the surveyors, and then watched, observed the intervention. But mostly conducting the study itself was probably the community health educators, the community outreach workers. They were the ones who actually implemented it because of the language [of the non-English-speaking community].

* * *

ANALYZING DATA: For most teams, collaboratively analyzing the data was difficult. Only one team conducted the analysis of data in a truly collaborative manner—again, at a kitchen table. A statistician entered the data and returned the data runs. The team then sat around the kitchen table and talked about what they thought the statistics meant and what was happening in the community at different times—for example, community-specific publicity—that might have affected the results.

Several researchers commented on the idea that "data was data" when analyzing quantitative data. They realized that the community could give different interpretations or could provide helpful perspectives on what the "potential inferences could be" but were not convinced that community collaboration on data analysis was particularly useful or important. One community partner remarked that this differentiation of role best utilized the skills and experience of the academic partner. Another participant commented:

* * *

[It was a team effort] because the data doesn't mean anything unless you put the community into it and the cultural variations to explain some of the things we were seeing.

* * *

DISSEMINATION: All seven teams in this evaluation reported participating in presentations of their study results to either community or scientific audiences, with four teams presenting data at both community and scientific gatherings. Two teams did not present their data back to the community.

One team discussed various ways they wanted to get the information from the study back to the community, as well as to scientific audiences. Each partner participated in all of the community forums, and each took the lead in writing articles, including peer-reviewed journal articles, with input from the others. They jointly developed a PowerPoint presentation of their study and results so that any team member could give the same talk. They worked together to ensure that the community members of the research team were comfortable with the science and that the academic partner was fully educated about the community. Two partners commented:

* * *

We decided that we needed to do community forums. So I went to all the community forums and then writing up journal articles, we've been involved in that. But we usually would have one person take lead on the journal article, then we all add and review and critique and edit. And then just making sure people get the information and then going to the different conferences and presenting. So I've been a part of that. But we all kind of take turns, we make sure everyone has a turn, as well as everyone is represented.

* * *

[The academic partner] from the beginning was always saying that the community owns the data, that's why you have to go back and do a community forum, we have to do this. And then the health educator [said], we'll lose our reputation and trust if we don't go back.

* * *

BALANCE OF POWER: Participants were asked to discuss the balance of power within their team. Four teams described their team as evenly balanced while the other three teams indicated that the academic partner was more in control. In two of the less balanced teams the community partners indicated that the lack of balance was acceptable to them. The lack of balance in one team was a source of contention. Team members described this power imbalance as the academic partner "carrying the ball," functioning as "point guard," "carrying more weight in the whole research project," and "controlling the study." Participants on two other teams commented:

* * *

The balance of participation was as expected, and on both sides of the equation, the community and the academic, because roles and responsibilities were very clearly defined.

* * *

Pretty much the whole gamut of activities that are involved in a research project, our community partners have always been involved as equals, but providing the community perspective.

* * *

Group Dynamics

Participants were asked to discuss their experience of conducting the project together. Specifically, they were asked about:

- Whether the amount and form of communication felt adequate;
- How often the research team communicated with each other;
- Their relationship working with their partner(s);
- Whether personnel turnover negatively impacted their project;
- Conflicts they faced and how they resolved them (or didn't);
- Whether they had partnership agreements, oral or written;
- Whether the benefits of participating in the project outweighed the costs.

COMMUNICATION: The level of communication was fairly high among all the groups. Some teams met in person monthly and spoke on the phone and emailed sometimes daily. Other teams communicated much less frequently, mostly by phone and/or email. One team went from weekly to monthly communication during one part of the study. While frequency and type of communication were not based on the geographic proximity of the partners, the teams that maintained frequent face-to-face communication resided and worked within the same area. One participant commented:

* * *

We were communicating on an ongoing basis because we had activities throughout the community. And that's one thing that I guess generated such a positive relationship.

* * *

RELATIONSHIPS/EXPERIENCE OF PROJECT: The level of satisfaction with working in the team varied, but was fairly high for all but one team. Two teams expressed effusive admiration for all members of the team. Four of the teams stated that they had very positive, "friendly and collegial" relationships, and that they felt listened to, respected, and understood. Four teams shared examples of discomfort with members of the team or with their partner, with three of those teams having conflict among members of the team. One team's conflict resulted in continued strained relationships even after the study was complete. Two teams ended the study with the belief that they would not be willing to work together again, especially with specific members of the team. The other five teams indicated an absolute willingness to work together with one team member stating, "Yes, in a heart beat" and another saying, "Yes, with clearer parameters." Other comments on team relationships included:

* * *

The very act of our collaboration became a living example and inspired others to get involved. And this collaboration has always been open-ended, anybody can come. In fact, people are always welcomed. And so it's an evolving collaboration.

* * *

It was never, when we sat at the table, this is the researchers, we're the community. It was more like everyone getting together, and hey, what are we going to do about this. And the only main difference between us was that [the academic partners] knew the statistical stuff that we didn't know. But they never ever made us feel like we didn't know anything. In fact, they made us feel like we were the experts and that they were learning.

* * *

I think I've learned how to be more collaborative, to insist that the community be involved when there's assessments going on, when there's distribution of funds, that the people who are affected need to be involved in the decision making. In that sense it's probably had the greatest impact on me.

* * *

It all seems like some sort of miracle that it all gets done, given the distances, the different disciplines of people involved, the different types of institutions. It was really very interesting. And the readiness of women to contribute was always very touching to me and still is.

* * *

TURNOVER: Five of the projects experienced significant challenges due to turnover of project personnel or senior staff from the community principal investigator's organization. Three of those projects had turnover in their community principal investigator between the pilot grant and the full grant, with two of those projects having turnover because the community principal investigators died from breast cancer. Two of those three projects also had a change in the executive director in addition to the community principal investigator. Turnover had both an emotional and an organizational impact on the projects. As two participants commented:

* * *

This was hard for us because we all, none of us wanted to see this happen. But [the community principal investigator] really experienced a decline in function that was hard to face and admit for all of us.

* * *

Because we'd worked together, or many of us had worked together on the pilot and we'd had a year working together putting the project, the application together, somehow I think it worked. I think we made it... I think it was okay. I don't think it changed anything in a major way.

* * *

CONFLICT: Three of the seven teams reported somewhat to significant challenges on their projects. Two of those teams had significant conflicts erupt between team members that could not be resolved through mediation or intervention by the CBCRP. One team's conflict was due to a perceived uneven balance of power between the community-based organization and the academic partner. The other conflict was due to a lack of understanding between the academic partner and the community organization about ownership of the data and future uses of the data (including who had the power to authorize other researchers to access the data). Reflecting on conflicts between a community-based organization and an academic partner, one partner said about community-based participatory research, "I think it's more complicated than people think."

Community principal investigators left their agencies at or toward the end of two of the projects. This caused conflict because the community and researcher principal investigators assumed they would take the project with them and it would no longer be associated with the community organization. In one of those situations, the community organization fought to keep the study. In the other situation, the CBCRP informed the community principal investigator and community organization that the study had to stay with the community organization. On this team, both community principal investigators had doctoral degrees, raising the possibility that each had a more academic orientation to their role in research, and assumed they could take the study with them, as is common in academia. Another participant commented about conflict:

* * *

Sometimes it becomes difficult to try and get work done. Academics are driven by certain kinds of expectations and community members, their expectations are different. So you definitely are going to have challenges. But the important thing is to be able to try and not lose sight of the bigger picture, to find answers to the challenges.

* * *

WRITTEN AGREEMENTS: Most teams did not have written partnership agreements for the two areas inquired about in the interview: ownership of data and handling disagreements. There was confusion among several of the teams about what was written down and what wasn't. Two teams talked about "guiding principles" that included a definition of collaboration and the need to create a safe environment in which to raise concerns. On three teams, the academic partners thought they owned the data, but the community organizations thought it was shared. Both members of one team assumed the academic partner owned the data, but it was never discussed. A member of another research team commented:

* * *

We had a discussion. We now have a written statement about that and policy on it, but at the time we didn't. Because we worked so well together and we all worked in a group, it was understood that the community owned the data.

* * *

BENEFITS VS. COSTS: Even with the difficulties stated above, all but one respondent said that the benefits of the collaboration outweighed the costs. Respondents expressed sentiments such as: "Oh, absolutely," "Without a doubt, on every level," "I was glad to do it, it was sort of a little bit of altruism there." One academic partner spoke of the importance of researchers of color to participate in community-based participatory research, but said that academia, in general, does not value community involvement, so the costs to advancement are great. Other research team members commented:

* * *

The basic drawback by doing community-based projects, especially research, is you spend so much time working in the field, working on the research, that it slows you down, in terms of being able to keep pace with your grant writing commitments and publication commitments that basically can help your academic career. So if you are doing community-based participatory research, you basically have to be cognizant of the fact that it will slow your career down.

* * *

I've been doing this for twelve years. If I felt that the benefits did not outweigh the costs, I would have stopped doing community-based participatory research.

* * *

I think researchers learned that it takes a lot more time, because you have to do a lot of relationship building.

* * *

Involvement of the Community Organization and Broader Community

Participants were asked to discuss the level of involvement of community members from outside the community-based organization and the level of involvement of the organization's staff and board members.

BROADER COMMUNITY INVOLVEMENT: Community members outside the community-based organization were significantly involved in two projects as members of the research teams, as interviewers, or through an active community advisory board. Two teams had virtually no involvement of outside community members. One of these had many community members on the research team, but they were all on the community-based organization's board of directors or staff. The other team held focus groups to help design the survey tool. However, community members taking part in focus groups were really participants in the study, because they had no power to make decisions or influence the study in any way other than providing comments for the researcher to interpret. Two research teams utilized community leaders to help recruit participants for their study. Members of other research teams stated:

* * *

At the community level the members of our local support group were very involved in putting together the details of the project, and acting as advisors. For instance, we took the intervention instruments and gave them to a pilot group. How long did it take? Was it understandable? And so on.

* * *

I think the other impact on those women who were involved in it from the beginning was that they were empowered to use their ideas and thoughts and to talk with other women, and be more forthright about having breast cancer and be more sharing about it.

* * *

COMMUNITY-BASED ORGANIZATION INVOLVEMENT: One team's community-based organization board and staff were deeply involved throughout the study, with numerous presentations and requests for input and guidance. Four teams included some community-based organization staff and volunteers in the research team or as representatives of the research project out in the community. Two teams involved the community-based organization staff and/or board at a minimal level, such as asking them for names of people to contact to help with recruitment. Members of two teams gave contrasting comments:

* * *

I [the community principal investigator] think probably the executive director was the only other person [in the organization] who was involved. And it was mostly moral support that I got from her regarding doing the work.

* * *

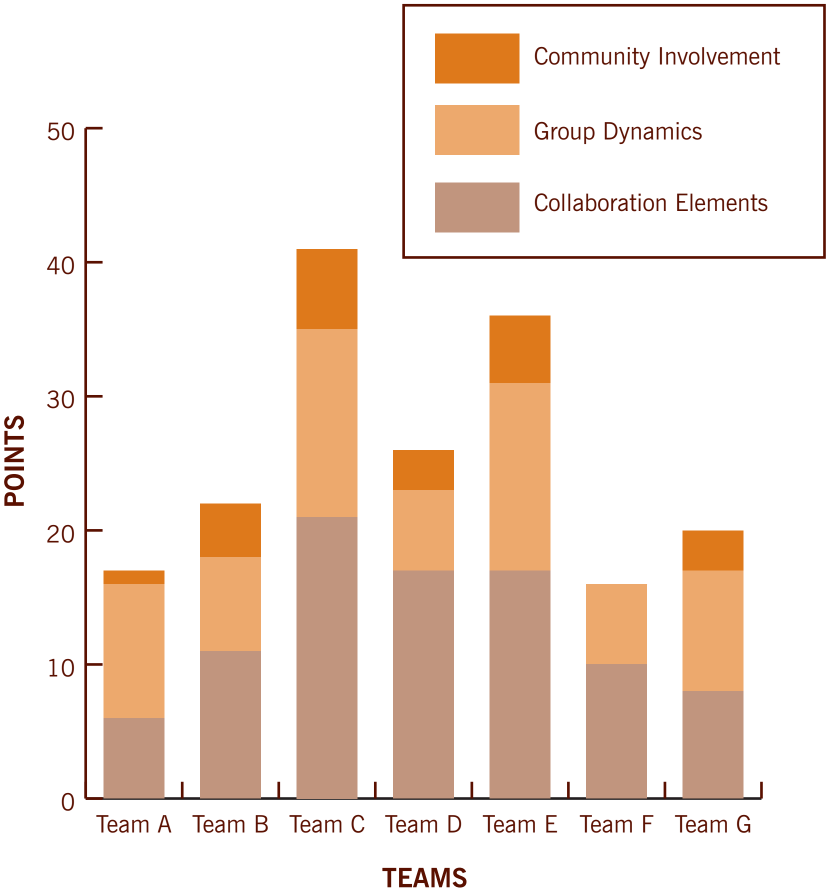
We reviewed everything with all three organizations and all their staff, all the staff that were appropriate, who were either involved in breast cancer, either worked in the…community, the directors of all the agencies, and we included the other organizations, not just the funded but community organizations… getting the president and their board involved in saying is this appropriate, is it okay if we go out. So we asked permission of everyone about doing the study, going on outreach, letting them know when it was going to occur, giving them feedback, having them review all our tools, and then also in all the community forums, helping us plan the community forums.

* * *

OVERALL PARTNERSHIP CHARACTERISTICS SCORES

A graph showing the combined point totals for each team can be seen in Figure 2. Three teams (C, D, and E) had partnership characteristics that more closely resembled characteristics of “authentic partnerships” as identified in the community-based participatory research literature. As one member of one of these teams said, “The collaboration drove the research.”

Figure 2: Combined Partnership Characteristics



RELATIONSHIP BETWEEN PARTNERSHIP CHARACTERISTICS AND OUTCOMES

When partnership characteristics were compared to outcomes for each team, the three teams ranked highest for partnership characteristics also ranked highest for outcomes (see Figure 3 below). The four teams ranked lowest on partnership characteristics also ranked lowest on outcomes. The correlation between partnership characteristic scores and outcome scores indicates that there may be some association between implementing community research collaboration projects according to generally accepted collaboration criteria and achieving positive outcomes with those projects.

Figure 3: CBPR Characteristics Compared to Outcomes

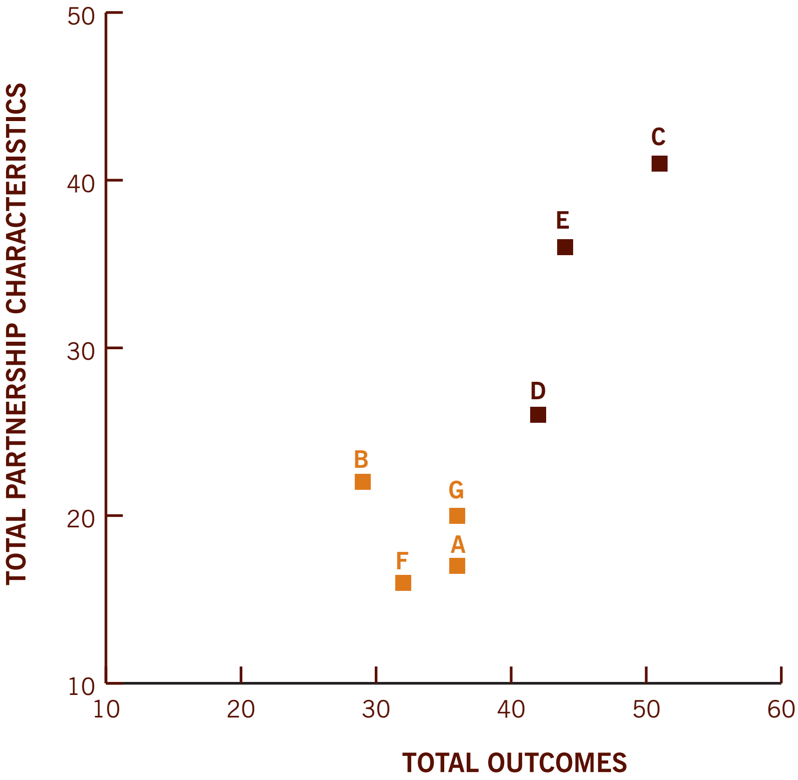


Table 5 lists the differences in partnership characteristic scores between the three teams who scored highest and the four teams who scored lowest for outcomes from their research projects. The three teams who scored highest for outcomes scored significantly higher on six key partnership characteristics than the four teams who scored lowest for outcomes. The six key partnership characteristics are:

- sharing power throughout the project,
- sharing participation in the question development,
- sharing participation in conducting the study,
- sharing participation in planning the methods,
- involvement of community members from outside the community organization's board and staff, and
- involvement of the organization's board and staff.

These characteristics might be important for encouraging all team members to feel like full partners and take responsibility for project completion, as well as ensuring positive outcomes with their study results.

The four teams who scored lowest for outcomes had their lowest partnership characteristics scores in:

- sharing power throughout the project,
- sharing methods development,
- community involvement,
- board/staff involvement, and
- sharing data analysis.

Regardless of their scores on outcomes, most teams scored well on several partnership characteristics. Most teams maintained good relations with their partners, participated in some level of dissemination, and all managed to overcome most of the study challenges. However, while all teams on average scored well in those areas, the high outcome teams, on average, still scored higher.

All teams had comparably low partnership scores for lack of written agreements and lack of sharing data analysis. Given the generally positive relationships the teams maintained, the lack of written agreements were only challenging for a couple of the teams. And sharing data analysis has been identified throughout the country as a challenge in community-based participatory research. Table 5 shows the average partnership characteristics score comparing the high outcome teams with the low outcome teams, and the difference in the average score, in order from the highest possible score of 3 to the lowest possible score of 0.

Table 5: Partnership Characteristics Differences Between High- and Low-Outcome Teams

PARTNERSHIP CHARACTERISTICS	HIGH-OUTCOME TEAMS AVERAGES (n=3)	LOW-OUTCOME TEAMS AVERAGES (n=4)	DIFFERENCE
Shared power throughout project	2.67	0.50	2.17
Shared question development	3.00	1.25	1.75
Shared conducting study	3.00	1.50	1.50
Shared methods planning	2.33	1.00	1.33
Community involvement	2.33	1.00	1.33
Board/staff involvement	2.33	1.00	1.33
Question from community	3.00	1.75	1.25
Level of communication	3.00	1.75	1.25
Shared data analysis	2.00	1.00	1.00
Relationship with partner(s)	2.67	1.75	0.92
Managed turnover disruption	2.00	1.25	0.75
Shared dissemination	2.33	1.75	0.58
Managed challenges in study	2.33	2.00	0.33
Written agreements	1.33	1.25	0.08

One research team member noted that the process of doing the research taught the team about collaboration:

* * *

> *This project actually brought out a lot of other ideas around what is truly community participatory research for us, and what does it mean to have a true partnership. And I think because [the academic partner] is such, just incredible about what a true partnership is, for us it helped us so that when we do our dissemination and whenever we go out to the community, we talk about this is community participatory research, this is what you need to have in place, and this is what a true partnership is. This project is the one that generated all that. So we didn't have anything in place during the project, but it made us think of all the things that groups would need in place. And so we're advising others on that.*

* * *

Conclusions

The Community Research Collaboration awards are an effective way to create meaningful partnerships of community members and researchers to conduct breast cancer research. While the development of authentic partnerships was inconsistent, collaboration was cited by most participants as adding important value to most steps in the research project.

Each CRC project reported successful outcomes in the four dimensions evaluated: (1) The CRC project improved knowledge, programs, and policies related to breast cancer; (2) participating in the CRC project positively impacted the quality of the research; (3) participating in the CRC project positively impacted the community partner(s) and members of the community; and (4) participating in the CRC project positively impacted the academic partner.

Each project also reported some success with each of the three partnership dimensions evaluated: (1) collaboration and power sharing by partners; (2) healthy group dynamics of team; and (3) involvement of broader community and community organization.

In this evaluation, those teams that more closely reflected authentic partnerships had the most successful outcomes evident from their research project and partnership. The three teams with the most successful outcomes from their research reported the highest involvement of both the broader community and the board and staff from their community organizations.

Although implementation of truly collaborative relationships was inconsistent among the teams, the lack of collaboration was not due to lack of interest or beliefs that it wasn't important. Some teams lacked models for collaboration in more technically sophisticated areas, such as data analysis. They also lacked funding to keep all partners involved in the dissemination stage, an understanding of the importance of clarifying assumptions, and written agreements.

Discussion

It ain't what you don't know that gets you into trouble. It's what you know for sure that just ain't so.

—Mark Twain

This evaluation uncovered team members' differing assumptions about: who owned the data, who owned the products developed through the studies, who would control access to the data after the study, whether the study would go with the community principal investigator if he or she left the community organization, how the partners would continue collaborating on dissemination after the formal funding period for the project was over, what and in what order community and scientific dissemination would occur, what affiliation would be used for community members in dissemination materials, and how the community organization would be identified in dissemination materials.

These differing assumptions significantly affected the ability of some teams to fully collaborate in a positive working relationship throughout their project. This is significant because the CRC projects implemented with the least collaboration and power sharing reported the least outcomes from their projects.

Given the many areas where teams did not have full agreement, it is remarkable that only three of the seven teams had conflicts. While collaborations have been noted as being time-consuming and challenging, the good will and trust between the individuals in the partnerships evaluated appears to have contributed to their success.

Moreover, further exploration of the misunderstandings is warranted. Some misunderstandings could be traced to assumptions that team members made about each other's culture; that is, the traditional rules and norms of academia vs. nonprofit organizations. For instance, in academia, researchers almost always take their research projects with them when they move to another institution, they own and control their data, and their affiliation is almost always listed as the institution where they are employed. In contrast, nonprofit organizations maintain their projects and reassign staff when a staff member departs, organizational affiliations extend to volunteers, and the community-based participatory research partnership is maintained with the organization, rather than with the individuals representing the organization. Not having discussed these potential issues in the early stages of the study, and not being aware of the differences that exist, could lead team members to make inaccurate assumptions.

The impact of turnover was significant on the projects included in this evaluation. Turnover during a four- to six-year project can be expected in collaborations with communities having a serious health issue, such as breast cancer, and with nonprofit organizations, where staff turnover every three to five years is the norm. This turnover does not need to cause conflicts unless, again, agreements have not been put into place.

Additionally, the academic partner may often take over the more scientific elements of the project, like data collection/storage and analysis. Yet community organizations can have long histories and experience in maintaining confidential material, such as personnel files and client records; they can also collaborate with data analysis, including quantitative analysis, and suggest variables to consider from their members' lived experience.

Conforming to the assumed roles of academic researchers may have also been affected by the high level of inclusion of community partners in the CRC projects evaluated who have professional degrees (75 percent have master's degrees or higher). Community partners with professional degrees may not question their assumptions about academic researchers. The high number of community partners with professional degrees in the projects evaluated here appears to be unusual in community-based participatory research, but it might be expected in collaborations around health issues, such as breast cancer, that have significant impact on individuals with higher incomes, greater years of education, and more professional positions. Professionals from the community partnering with other professionals, however, can add to the difficulty of seeing and negotiating around differences between community and academic researcher interests.

* * *

If you're in a coalition and you're comfortable, you know it's not a broad enough coalition.

—Bernice Johnson Reagon

* * *

The inclusion of members of the broader community and members of the staff and board of the community organization were significantly greater in the teams with more successful outcomes. Including members of the broader community on the research team might help to ensure that nonprofessional community interests are considered and could additionally assist the collaboration in managing turnover. The inclusion of staff and board members of the community organization on the research team could help to ensure that the organization's interests are considered, for example, in areas like publications.

More individuals involved in the research projects could also increase the complexity of the group dynamics, especially if those individuals increase the level of diversity within the team. Increasing the size of the teams may therefore require more attention to the process of collaboration, not just the outcomes. As shown more fully in our previous evaluation report, benefits appear to accrue to community members and community organizations who participate in community-based participatory research, so the suggestion to expand the number and diversity of individuals involved from the community side of the collaboration could benefit both the research project and the community members.

Limitations

This evaluation has several limitations. One is the inability to weight the importance of different outcomes or partnership characteristics of the projects. For instance, should having written agreements be weighted the same as sharing power throughout the study? It is a value judgment to decide that these two partnership characteristics, when both performed well, should be weighted the same.

This evaluation is further limited in that it focuses on participants' perceptions, experiences, and views, and not on any external measures or validation. However, as individuals within each team were interviewed individually, the researcher was able to rely on consistency among team members to validate the findings.

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.

Failure to achieve some of the outcomes is possibly due to external forces (i.e., lack of media interest in certain communities could limit media outcomes). Additionally, as this evaluation captured a particular point in time, additional publications and funding that have derived from these projects were not included (although anecdotal reports show successful outcomes in these two areas).

Finally, the evaluator did not consider whether the results of the research projects evaluated were important or statistically significant; all of the studies listed as "completed" by the CBCRP within the time frame were included. This is a limitation because if the seven projects evaluated here do not have statistically significant results or are less important to the field of breast cancer research, they can be expected to have fewer outcomes and little impact.

Recommendations

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

1. Continue supporting, strengthening, and possibly even expanding the CRC awards. Support would be most useful in providing technical assistance to the CRC teams to ensure full collaboration during all phases of the project, including data analysis and dissemination.
2. Develop best practices materials which provide models of collaboration throughout the research project and examples of meaningful inclusion of members of the broader community to help teams adhere more closely to community-based participatory research principles.
3. Require the development of memoranda of understanding by CRC teams and board resolutions from the involved community organizations that specifically delineate agreements regarding power sharing, communication, personnel turnover (including the possibility of the community principal investigator leaving), ownership of data and other project related outcomes, handling of budget, dissemination of results to community and to scientific audiences, use of affiliations in publication materials, use of community-based organization identification in publication materials, and a conflict resolution plan.
4. Provide funding for dissemination of successful project results to allow partnerships to continue working together through this important step.
5. Participate in efforts to recruit researchers to conduct community-based participatory research. Consider supporting programs that focus on recruiting community members (especially women of color) to earn advanced research studies degrees and supporting efforts to make institutional change that reward community collaboration in academia.
6. Continue to explore the relationship between outcomes and partnership characteristics in these awards.
7. Further explore reasons for the lower-scoring outcomes and partnership characteristics uncovered in this evaluation and consider interventions to improve these variables.
8. Continue to evaluate CRC awards and disseminate findings to larger audiences.

Based on the results of this evaluation, collaborative research teams should:

1. Invest in the relationship. Participate in activities that allow for the development of respect, understanding, and trust.
2. Share power and work throughout the study, especially during data analysis and dissemination.
3. Prepare for disruptions and turnover, and have clear agreements about how individuals will be replaced, trained, and integrated into the team.

4. Have written agreements among the collaborative team and with the leadership and board of directors of any involved community-based organizations. Include as many elements and potential eventualities of the project as can be considered.
5. Discuss expectations about dissemination including how and when study results will be reported and to whom.
6. Communicate openly and frequently about the process of the collaboration, not just the project and outcomes.
7. Involve larger groups of community members in the collaboration as research team members, research assistants, and advisors.
8. Involve the staff and board from any participating community organizations to ensure shared ownership of the project and its outcomes, and to ensure that capacity building is a core component of the project.

Based on the results of this evaluation, evaluators of community-based participatory research should:

1. Continue to evaluate the effectiveness of community-based participatory research projects.
2. Expand on and strengthen numeric likert scales as evaluation tools.
3. Consider weighting the importance of partnership characteristics and outcomes.
4. Investigate the qualities of individuals and of partnerships that enhance community-based participatory research and allow for trust to build.
5. Conduct cost/benefit evaluations on collaboration at each step of the research study (such as the data analysis step) and the inclusion of more individuals from diverse backgrounds (i.e., race/ethnicity, education level, socio-economic status) on the collaboration team.

References

Cornwall A. and Jewkes R. (1995). What is participatory research? *Soc Sci Med*, 41(12), 1667-1676

Fadem P., Minkler M., Perry M., Blum K., Moore L., and Rogers J. (2003). Ethical Challenges in Community Based Participatory Research: A Case Study from the San Francisco Bay Area Disability Community. In M. Minkler and N. Wallerstein (Eds.), *Community Based Participatory Research for Health* (pp. 242-262). San Francisco, CA: Jossey-Bass

Goldstein E., Freedman B., Richards A., and Grinstead O. (2000). *Conducting Community-Based Research: The Legacy Project.* University of California, San Francisco, Center for AIDS Prevention Studies

Hagey R.S. (1997). The use and abuse of participatory action research. *Chronic Dis Can,* 18(1), 1-4

Hatch J., Moss N., Saran A., Presley-Cantrell L., and Mallory C. (1993). Community research: partnership in black communities. *Am J Prev Med,* 9(6 Suppl), 27-31; discussion 32-24

Israel B.A., Schulz A.J., Parker E.A., and Becker A.B. (1998). Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health,* 19, 173-202

Lantz P.M., Viruell-Fuentes E., Israel B.A., Softley D., and Guzman R. (2001). Can communities and academia work together on public health research? Evaluation results from a community-based participatory research partnership in Detroit. *J Urban Health,* 78(3), 495-507

Marincowitz G.J. (2003). How to use participatory action research in primary care. *Fam Pract,* 20(5), 595-600

Maselli D., Lys J.-A., and Schmid J. (2004). *Improving Impacts of Research Partnerships.* Berne: Swiss Commission for Research Partnerships with Developing Countries KFPE

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.

Additionally, we would like to thank the following people for their contributions to this study:

Walter Price, Dr.P.H.
CBCRP Community Initiatives Manager

Jelena Simjanovic
CBCRP Program Assistant

Judy MacLean
Consultant, editor

Sally Goldin, Tell Me A Story
Transcriber

APPENDIX A

CBCRP CRC Projects Study Results

A Support Group Alternative for Rural and Isolated Women

Found that women randomized to receive the One in Eight workbook-journal reported greater reductions in depression symptoms at a six-month follow-up assessment than women who received usual care. Finding alternatives to face-to-face support groups is important for geographically-isolated individuals. This research and intervention have widespread applicability to women isolated by other situations or conditions, or who do not choose to attend face-to-face support groups.

Breast Cancer Risk Factors: Lesbian and Heterosexual Women

Lesbians may have a higher risk for developing breast cancer than heterosexual women, based on this sample, but not the previously-reported two or three times higher risk. Accurate risk assessment of communities with common characteristics adds valuable information for outreach efforts both within and outside the community of interest. Knowing that lesbians have a possibly higher risk of breast cancer allows 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 communities have the lowest screening rates, in aggregate, of all U.S. ethnic populations. A breast health education program was implemented to increase mammography rates among Hmong women, who 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 intervention. The intervention program had a significant effect on whether or not a woman went in for screening.

Do Community Cancer Support Groups Reduce Physiologic Stress?

Found that 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 of group therapy as women in university-setting groups. This study suggests that community groups are as effective at serving women with primary breast cancer as groups set in academic and clinical institutions.

Increasing Breast Health Access for Women with Disabilities

Results show that 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 her number of physical limitations. Project findings 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

Found that women who drank at least two alcoholic drinks per day were more than twice as likely to be diagnosed with breast cancer as women who drank less, despite similar distributions of several known breast cancer risk factors in a county with a high rate of the disease. This suggests that even in this high-risk population, risk may be modifiable. By increasing knowledge of breast cancer etiology, studies may enhance possibilities for breast cancer prevention. Collaborative studies conducted in communities with high rates of breast cancer can also provide insight into the causes of the disease.

Samoans and Breast Cancer: Evaluation of a Theory-based Program

This study found that Samoan American women were more likely to have ever had a mammogram if they had: positive group norms for obtaining a mammogram, health insurance, positive belief in the efficacy of mammography, fewer misconceptions regarding the causes of breast cancer, fewer culture-specific beliefs regarding the causes of breast cancer, and higher self-efficacy. The project could enhance breast cancer awareness, increase screening and early detection rates, and over time, could potentially lower morbidity and mortality from the disease in this underserved community.

APPENDIX B

Peer Reviewed Articles and Abstracts that Resulted from CRC Grants in this Evaluation

Articles

1. Angell K., Kreshka M.A., McCoy R., Donnelly P., Turner-Cobb J., Graddy K., Kraemer H.C., and Koopman C. (2003). Psychosocial Intervention for Rural Women with Breast Cancer: The Sierra Stanford Partnership, *Journal of General Internal Medicine,* 18(7), 499-507

2. Benz C.C., Clarke C.A., and Moore D.H. (2003). Geographic Excess of Estrogen Receptor-Positive Breast Cancer, *Cancer Epidemiology Biomarkers and Prevention,* 12, 1523-1527

3. Collie K., Wong P., Tilston J., Butler D., Turner-Cobb J., Kreshka M.A., Parsons R., Graddy K., Cheasty J.D., and Koopman C. (2005). Self-Efficacy, Coping and Difficulties Interacting with Health Care Professionals Among Women Living with Breast Cancer in Rural Communities, *Psycho Oncology,* 14, 901-912

4. Cordova M.J., Giese-Davis J., Golant M., Kronenwetter C., Chang V., McFarlin S., Spiegel D. (2003). Mood Disturbance in Community Cancer Support Groups: The Role of Emotional Suppression and Fighting Spirit, *Journal of Psychosomatic Research,* 55, 461–467

5. Dibble S.L., Roberts S.A., Davids H.R., Paul S.M. and Scanlon J.L .(Oct. 6, 1999). A Comparison of Breast Cancer Risk Factor Distributions between Lesbian and Bisexual Women. *MS JAMA Online* 282(13)

6. Dibble S., Roberts S.A., Robertson P.A., Paul S.M. (2002). Risk Factors for Ovarian Cancer: Lesbian and Heterosexual Women. *Oncology Nursing Forum Online Journal,* 29(1)

7. Dibble S., Roberts S.A., Nussey B. (2004). Comparing Breast Cancer Risk Between Lesbians and Their Heterosexual Sisters. *Women's Health Issues* 14, 60-68

8. Hwang E.S., Shiboski C.T., Farren G., Benz C.C., and Wrensch M. (2005). Risk Factors for Estrogen Receptor-Positive Breast Cancer. *Archives of Surgery,* 140(1), 58-62

9. Kagawa-Singer M., Foo M.A., Tanjasiri S.P. 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

10. Koopman C., Angell K., Turner-Cobb J., Kreshka, M.A., Donnelly P., McCoy R., Turkseven A., Graddy K., Giese-Davis J., and Spiegel D. (2001). Distress, Coping, and Social Support Among Rural Women Recently Diagnosed with Primary Breast Cancer. *The Breast Journal* 7(1), 1-9

11. Mishra S.I., Bastani R., Huang D., Luce P.H., and Baquet C.R. (2007) Mammography Screening and Pacific Islanders: Role of Cultural and Psychosocial Factors. *Journal of Cancer Education,* accepted for publication.

12. Nguyen T.N., Kagawa-Singer M., Tanjasiri S., and Foo M. (2003). Vietnamese American Women's Health: A Community Perspective. *Amerasia Journal* 29, 1183-198

13. Owen J.E., Giese-Davis J., Cordova M., Kronenwetter C., Golant M., and Spiegel D. (Aug 2006). Self-Report and Linguistic Indicators of Emotional Expression in Narratives as Predictors of Adjustment to Cancer. *Journal of Behavioral Medicine,* 29(4):335-45

14. Palesh O., Shaffer T., Larson J., Edsall S., Chen X.H., Koopman C., Turner-Cobb J., Kreshka M.A., Graddy K., and Parsons R. (2006). Emotional Self-Efficacy, Social Support, and Stressful Life Events in Relation to Mood Disturbance among Women Living With Breast Cancer in Rural Communities. *The Breast Journal,* 12(2), 123-129

15. Roberts S.A., Dibble S., Nussey B., Casey K. (2003). Cardiovascular Disease Risks in Lesbians. *Women's Health Issues* 13, 167-174

16. Roberts S.A., Dibble S.L., Scanlon J.L., Paul S.M. and Davids H.R. (1998). Differences in Risk Factors for Breast Cancer: Lesbian and Heterosexual Women. *Journal of the Gay and Lesbian Medical Association,* 2(3), 93-101

17. Tanjasiri S.P., Kagawa-Singer M., Nguyen T.-Y., Foo M.A. (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

18. Wrensch M., Chew T. Farren G., Barlow J., Belli F., Clarke C., Erdmann C.A., Lee M., Moghadassi M., Peskin-Mentzer R., Quesenberry C.P. Jr., Souders-Mason V., Spence L., Suzuki M., and Gould M. (2003). Risk Factors for Breast Cancer in a Population with High Incidence Rates. *Breast Cancer Research* 5(4):R, 88-102

Abstracts

1. Koopman C., Kreshka M.A., Bodai B.I., Nakata T., Wolf H., Chen X.H., Angell K., Graddy K., McCoy R., and Collie K. (2006). A Randomized Study of Alternative Support for Rural and Isolated Women in an HMO: Effects On Depression, PTSD and Emotional Coping. *Annals of Behavioral Medicine*, 31, Suppl. S134

APPENDIX C

Products and Materials from CRC Grants 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 D

List of CRC Teams Interviewed for this Evaluation

Note: Team codes A-G 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, Community Principal Investigator, National Office of Samoan Affairs

Shiraz Mishra, Academic Principal Investigator, University of California Irvine

Breast Cancer Risk Factors: Lesbian and Heterosexual Women

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

Doreth Williams-Flournoy, Executive Director, Lyon Martin Women's Health Services

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

Increasing Breast Health Access for Women with Disabilities

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

Florita Toveg, Manager, Breast Health Access for Women with Disabilities (BHAWD)

Ann Cupulo-Freeman, Community Principal Investigator, Alta Bates Summit Medical Center

Do Community Cancer Support Groups Reduce Physiologic Stress?

Mitch Golant, Community Principal Investigator, Wellness Community

David Spiegel, Academic Principal Investigator, Stanford University

Janine Giese-Davis, Academic Principal Investigator, Stanford University

Carol Kronenwetter, Community Principal Investigator, Cancer Support Community

Morton Lieberman, Academic Consultant

Marin County Breast Cancer Study of Adolescent Risk Factors

Janice Barlow, Executive Director, Marin Breast Cancer Watch

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

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

Breast Health Project for Hmong Women and Men

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

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

Mai Chew Chao, Community Outreach Worker

A Support Group Alternative for Rural and Isolated Women

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

Cheryl Koopman, Academic Principal Investigator, Stanford Health Center