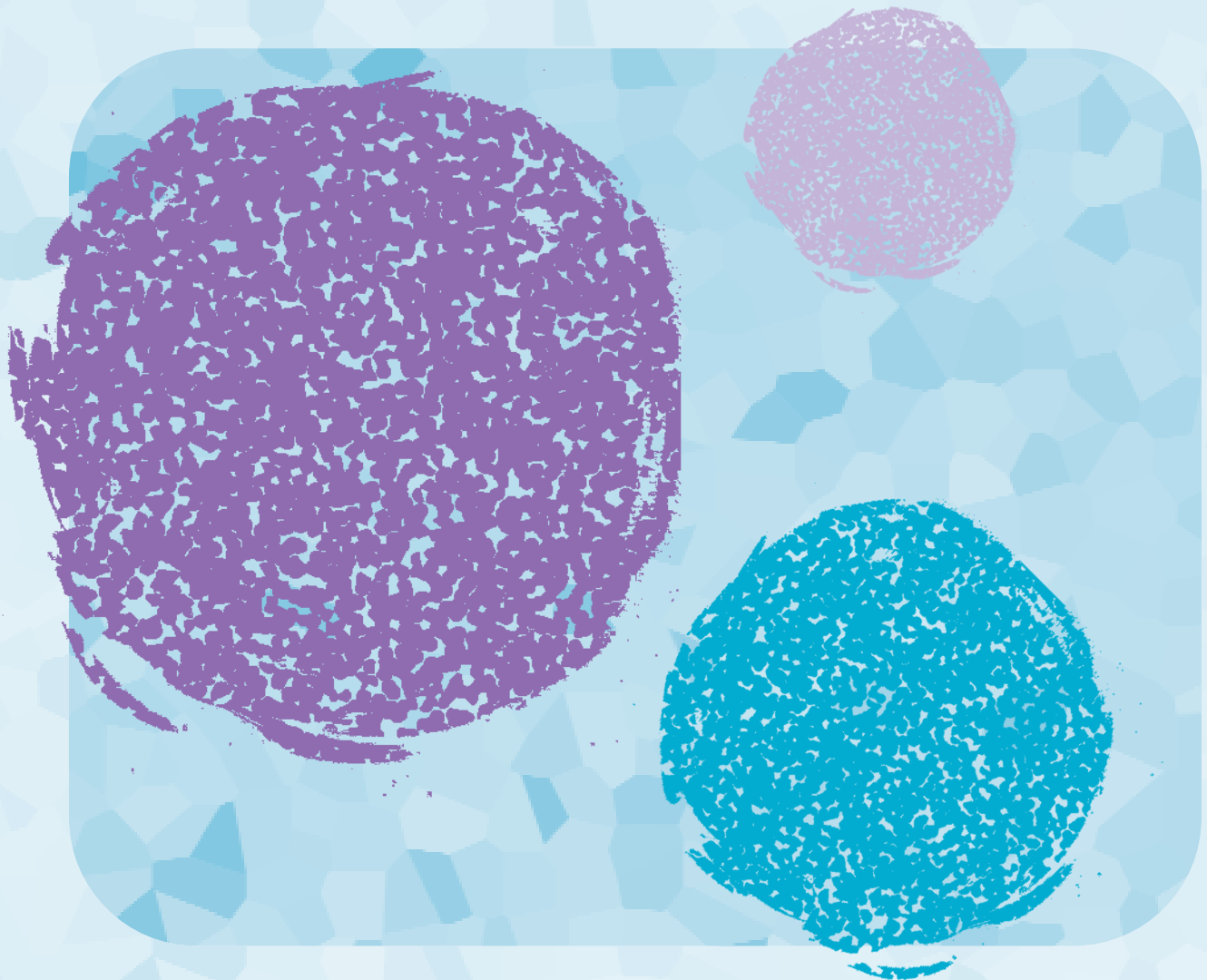


SEPTEMBER 2001

COMMUNITY RESEARCH
COLLABORATION AWARDS

**Report on the Evaluation
& Capacity Expansion Project**

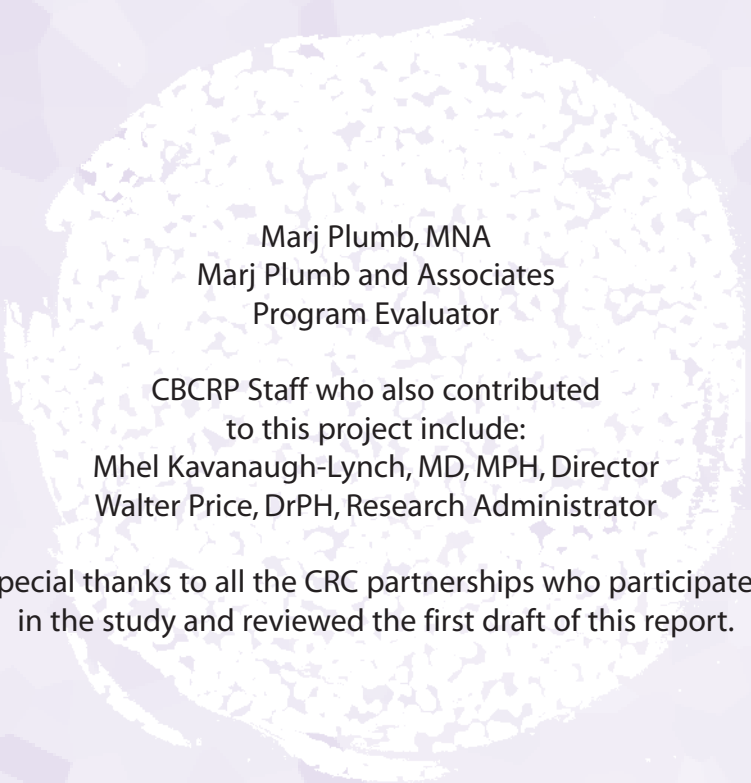


CALIFORNIA
BREAST CANCER RESEARCH PROGRAM

Community Research Collaboration Awards

Report on the Evaluation and Capacity Expansion Project

California Breast Cancer Research Program



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I. INTRODUCTION

In 1993, the California legislature responded to breast cancer advocates' pressure for more research funding to fight the disease by asking the University of California to establish and administer the California Breast Cancer Research Program (CBCRP). The CBCRP's mission is to reduce the impact of breast cancer in California by supporting research on the disease and facilitating the dissemination of research findings and their translation into public health practice. The CBCRP initiated the Community Research Collaboration (CRC) Awards in 1997 to bring community members and experienced research scientists together to study breast cancer-related issues that are of interest to both. The CRC Awards require a partnership between community members (such as breast cancer advocacy organizations) and research scientists.

The CRC Awards are modeled on Participatory Research (PR) as promoted by Dr. Larry Green. He defines Participatory Research as “systemic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or affecting social change” (George & Green, 1998-99). The partnership works together to identify the research question, develop the research plan, carry out the research, interpret the results, and disseminate information to the community.

PR, and the similar Participatory Action Research, is unique in the role the community of interest plays in the research project itself. Community members are equal partners in the research project. They have power in the development, implementation, and analysis of the research, and are able and willing to use the research to take action or create social change. PR is carried out with and by local people, not on them (Cornwall and Jewkes, 1995). It places the community, rather than the researcher or even the research question, at the center of the research paradigm. Since 1997, the CBCRP has awarded a total of \$4.6 million to 12 Community Research Collaborations, funding a wide variety of projects, including:

- a community-based workbook for helping rural cancer patients
- a method for increasing annual recall in state early detection programs
- breast cancer risk factors of lesbian and heterosexual women
- breast cancer screening in Hmong American communities
- adolescent risk factors for breast cancer in Marin County
- culturally appropriate breast care for Samoans and Koreans
- breast health access for women with disabilities
- community cancer support groups, retreats, and peer navigators
- issues women with breast cancer face when they return to work

In May 2000, the CBCRP began a process of evaluation of the CRC Award's program/funding mechanism. The consulting firm Marj Plumb and Associates interviewed awardees and applicants who had not received funding to assess the strengths and weaknesses of the CRC Awards. We gathered information on:

- the roles of the research partners;
- the nature of the research partners' involvement in the studies;
- suggestions for improving the CRC funding mechanism;
- lessons awardees and rejected applicants had learned that could foster strong collaborations between community members and academic researchers in the future.

II. MAJOR FINDINGS OF EVALUATION

The CBCRP CRC Awards have succeeded in getting research funds into communities affected by breast cancer and empowering these communities to participate as full partners in the research process. Including affected communities in the research process has added to the research milieu questions for study that might not have been considered. Because collaborative research can be time-consuming and complex for both the community and traditional research partners, we recommend improvements that will strengthen the awards and support the development of research collaborations.

Successes:

We identified successes within both the concept and implementation of participatory community-academic research collaboration.

- I. The CBCRP CRC Awards have given communities of women affected by breast cancer the power to formulate and initiate research projects addressing questions of concern to them. The majority of the community collaborators were breast cancer survivors.
- II. The program also supported research with populations not often so included such as: women who are (1) disabled, (2) rural, (3) lesbians, (4) of Samoan heritage, (5) of Korean heritage, (6) of Hmong heritage.
- III. The CBCRP supported several studies through re-writes and re-application. This is a much needed service component when introducing non-research communities into the research milieu.
- IV. The CBCRP has facilitated relationships between community groups and some of the most committed, community-sensitive academic researchers in California. The researchers' choices of research questions, methods, and implementation made clear the importance of the collaborations.

“We had a 99% follow-up rate. That is unheard of in research. The community partners were apologizing that they lost one woman to follow-up. We were teasing them that it was a good thing that they lost one woman or no one would have believed the study was for real”

– Academic Collaborator

Areas for Improvement:

Our evaluation also identified barriers to application and research implementation that the CBCRP should address to ensure successful awards. These include:

- I. The CBCRP needs to take the initiative in communicating with community groups. Community groups are at a distinct disadvantage when trying to understand the policies and procedures of a research funding institution. In the studies the CBCRP funded, community groups were not able to consistently participate as truly equal partners. The CBCRP should take the initiative to increase communication with the funded partnerships and create opportunities for the CRCs to learn from each other.
- II. Funding limits and delays, as well as the timing of applications and awards, make continuity difficult for the community-academic collaborations. Research partners have to expend energy that could be better used on the collaborative research trying to fill funding gaps and ensure data completion for future grant applications.
- III. Funding service delivery during or after the awards, would support the community agency's involvement in the research study and ensure a continuity of services to clients.

III. METHODS

The CBCRP contracted with the consulting firm Marj Plumb and Associates to conduct a process evaluation of the CRC Awards. The main goal was to gather practical information that the staff and Council of the CBCRP could use to improve the program.

We sent letters announcing the evaluation were sent to 31 current and past recipients of the CRC award as well as to 25 applicants who did not receive funding. The letters described the purpose and method of the study, and also encouraged participation. We conducted a total of 17 telephone interviews, 15 with current or past award recipients, representing nine projects. We also conducted two interviews with researchers who had unsuccessfully applied for funding. We developed the 11 open-ended interview questions in consultation with CBCRP staff (see Appendix I for questions). When necessary, we clarified questions and asked further probing questions to explore a participant's responses. The interviews lasted 45-60 minutes each during which time we took detailed notes. To provide additional context and insight into the telephone interviews, we collected secondary data by reviewing all of the grant applications and progress reports from the nine funded grant proposals associated with the 15 respondents who had received CRC Awards. After conducting the interviews, we compiled the notes, identified salient themes, and pulled descriptive quotes.

One limitation of this evaluation is the small number of respondents who had unsuccessfully applied for funding. Time constraints limited the number of these interviews.

IV. DESCRIPTION OF THE RESEARCH PROJECTS THAT PARTICIPATED IN THE EVALUATION

The evaluation covered nine funded research projects. These projects involved very different communities, including the following:

- Women with breast cancer (stages 1-3) living in the San Francisco Bay Area
- Low-income women with breast cancer
- Recently diagnosed underserved, rural women with primary breast cancer
- Adult women living in Marin County
- California lesbians over 40 and their heterosexual friends and sisters
- Samoan women in Los Angeles and Orange Counties
- Korean women in the Los Angeles area
- Newly diagnosed women in the Santa Cruz area
- Women with primary breast cancer living in Northern California

V. FINDINGS

We asked respondents to address four specific aspects of participatory research: the collaboration and application process, the purpose of the research, the involvement of the target community, and explicit agreements to resolve differences. The collaborations varied greatly in each of these four critical areas.

1. Description of the Collaboration in the Application Process.

A key element in Participatory Research (PR) is the origin or development of the research question (Hagey, 1997; George & Green, 1998-99). While the CRC Awards are intended to ensure that communities impacted by breast cancer *can* initiate research projects that concerns them, researchers based in academic settings may also initiate the collaborations. However, the research question must be shown to be of importance to the community. Of the nine research projects covered by this evaluation:

- a. Members of the affected community initiated six of the collaborations by developing the question(s) for research and actively seeking out academic collaborators prior to submission of the grant application;
- b. Two projects consisted of teams who had worked together prior to applying for funding. One of those teams had received previous research funding; the other had worked together without funding.
- c. An academic researcher initiated one of the projects. The community partner she had chosen to work with, however, had already seen the application and was concurrently looking for an academic researcher.

Three community collaborators described their involvement in the CRCs:

“I actually started to apply three times. The first time was when I was still in treatment for breast cancer. I went to the research symposium in Sacramento. I was really interested in the CRCs. I realized that for me the most important thing during my treatment was the peer navigator. I knew that I wasn’t ready for a support group, but I wanted to speak to someone who had been there and done that. The information I was getting from physicians was so conflicting.”

– Community Collaborator

“It was my idea. We saw that women with cancer were having difficulty getting benefits, and dealing with housing and employment discrimination. We were wondering how come some women did really well and others didn’t.”

– Community Collaborator

“I was the one who took it upon myself to find an epidemiologist. I made many, many phone calls. It was no small task. Lots of dead ends. Then I spoke with a doctor who thought he knew someone who would work with us. She was a former student of his. She wanted us to come with our own questions. She told us to meet weekly. She gave us epi journals to read. Two of the four community women had some medical background. We did a lot of reading on the current research.”

– Community Collaborator

2. Purpose of the Research

Tools for Social/Political Change. PR differs from traditional research in that the goal is not only to answer questions but also to give communities the tools they need to create social and political change. Those tools can include the results of the research, which can be used to impact policy, or the development of research

skills within a community, which can then produce more independent researchers. Conducting research should therefore provide individuals and communities with opportunities for education and empowerment. The results should also be useful for improving the lives and life conditions of the community being researched (Roe, 1995).

All of the community collaborators mentioned actions that they believed could result from their research. These included the following:

- policy changes
- improved provider training
- media attention to the issue
- improvements in state-of-the-art treatment and provider best practices
- assistance in raising funds for services
- further support for research collaborations
- increased quality of care

Developing Community Members' Research Skills. Another component of PR is the development of research skills among community members. All of the collaborations included community members who either had the demographic characteristics of those being studied (race, sexual orientation) or were breast cancer survivors. None had formal research experience, although almost all of the projects included in this evaluation had at least one community member who had some clinical training (nurse, social worker, physical therapist, clinical psychologist, physician) or who was involved in providing services in their organization. Therefore, those community researchers with some level of familiarity of medical/health terms and research concepts brought expertise to the collaboration that went beyond knowledge of the community or access to the research subjects. All community members expressed an increase in their understanding of research methods through their involvement in the project and a desire to continue using that knowledge to further their community's involvement in research. Some also expressed unintended positive effects on their clinical practices and lives, as exemplified by the following quote:

“ I was trained as a clinician many years ago, so I had some training in research but it was not functional. I felt privileged to be a part of this research team; I was learning something new. A tremendous amount changed in my knowledge and use of research from the simple technical level – how do you do assessments – to a broader theoretical understanding about how I think about what I am doing as a clinician. I've had various success and failure with clients over time. This experience has given me a team to talk to, the ability and awareness to do literature searches, to dig more deeply into my clinical practice.”

– Community Collaborator

3. Involvement of the Target Community.

Research has often been considered the domain of trained professionals. Concerns over scientific rigor are often used to create a hierarchy, with the academic researcher maintaining total control of research methods (Wing, 1998). However, decisions about how the research gets done — who is researched, how they are researched, where they are researched — have tremendous impact not only on whether the research has validity within the community being researched, but also on the science (Brown, 1992). True collaboration between community members and academic researchers is a hallmark of PR and is considered essential when the study and the interpretation of findings are important to all involved. Researchers face the challenge of designing models for collaboration that maximize the potential for community participation (Hatch, 1993). One academic researcher described a particular challenge for her collaboration:

“We had two problems with the community. One was the informed consent process. Our institution has a rigid informed consent statement that has to be used. There was no leeway to reword it, but the community wanted to. They felt the consent form would be upsetting to the women. After quite a bit of talking we achieved a compromise — we printed the consent form on lavender paper. They are very oriented toward color and aesthetics. We would never have thought of that.”

– *Academic Collaborator*

The collaborations we evaluated were weakest in community involvement in the research design, implementation, and analysis of data. Four groups reported intensive community involvement beyond those community members who were active collaborators on the research team. This involvement included holding community meetings; meeting with core groups of community members over an extended period of time; and having clients review the proposal, research methods, and tools to provide feedback. For those projects with minimal community involvement outside of the collaborators, the three most common reasons given were:

- As an organization working in the community they felt they could represent the community’s interest
- An advisory committee was pulled together, although it met infrequently
- The researchers were members of the target community

One researcher describes an informal method of community involvement:

“Involve ment of members of the target community wasn’t formal because we are a part of the target community. We did a number of things and then we ran ideas past other people in the community to make sure we didn’t have too narrow of a focus. She had folks at her organization and I had friends and colleagues.”

– *Academic Collaborator*

Most of the teams discussed pulling together advisory groups to review the interpretation or analysis of the research results. Two teams felt that the community was not as involved in the analysis as it should have been. Of those teams who did share the results with members of the community, most shared the analysis and asked for feedback, rather than sharing the data and seeing what analysis the community members would suggest.

“We talked about the analysis with the community advisory board to figure out whether our interpretation was the same as theirs. But, sometimes it’s better to not give your interpretation first. That’s what I’m going to do next time — show people the data and then let them give an interpretation first. You get multiple views on the same truth and it may represent the community better.”

– *Academic Collaborator*

The written application proposals of the nine funded projects varied greatly in their descriptions of community involvement. While the Collaborative Elements account for 50% of the total possible score for the proposal, out of a total of five pages for each proposal, the discussion of collaboration ranged from a minimum of one paragraph to a maximum of one page. The proposals had an average of 11 letters of support, with the range from four to 20 letters. One application included seven letters of support, but they were all from individuals and organizations that were part of the research team. The applications provided minimal evidence of true community involvement.

4. Explicit Agreements to Resolve Differences.

When community members work with traditional academic researchers, both parties need to understand the inherent power dynamics (Hagey, 1997). Power dynamics become complicated as the collaboration brings participants' very different goals into play. For the community, the primary goal is often some form of action (more or better services, changes in policies). For the academic researcher, the primary goal is knowledge and understanding (Hatch, 1993; Perkins and Wandersman, 1990). For the community to benefit from the research, it is essential that the partnership set up conditions for the collaboration and keep both community participants and academic researchers in control (Hall, 1992.) A healthy collaboration requires clearly defined roles and responsibilities, as well as the flexibility to re-negotiate those roles and responsibilities (Schensul, 1999).

All of those interviewed expressed a clear plan for resolving differences. Some of those plans were relatively informal ("We agreed to talk through any problems,") and some were formal ("We included an arbitrator in the grant budget"). Some of the projects decided to divide areas of responsibility — the academic principal investigator was responsible for the research and the community principal investigator was responsible for the community involvement. Others said conflicts did not arise because of mutual respect for what each partner brought to the team.

Those community collaborators who actually worked in a team of community members felt that having more than one community member was important to balance the power of the academic researcher, and, often, the academic institution. Those who had disputes that were addressed within the study period succeeded in working out their differences. Disagreements that did not get resolved prior to the completion of the study did occur within at least one group. The following reflects two views on conflict resolution within the collaborations:

"How we resolved one conflict is we sat down and talked about the pros and cons of the two options. Everyone felt strongly. We decided to have a six-month trial with parameters."

– *Community Collaborator*

"It has required a lot of compromising on everyone's part. My job is to maintain the scientific rigorness of the study. I've needed to be the heavy and have felt the heat of this role. We have discussions. They at first don't understand. They think about it some more. They come around to realizing the study will be more sound. When they don't accept what I say I get consultation to check out whether I'm correct. We've evolved this process over time."

– *Academic Collaborator*

All research projects included members of the community being studied as community collaborators. Some of the traditional researchers were also members of the communities being studied. Community participation ranged from community collaborators being members of the research team, at minimum, to patient-heavy Community Advisory Boards and community meetings where the research teams discussed the project and solicited input. One community collaborator described how her team involved the community in the research:

“Four of us were members of the nonprofit organization we submitted the application under. We attended monthly board meetings to inform the organization about what direction the research was going. We held monthly forums at a centrally-located hospital to get input from the community. Mostly breast cancer activists attended, plus some men (there was a prostate cancer support group during the week at the same facility.) We would invite speakers, but before the speakers spoke, we would update people on the grant application and, once funded, on the progress of the research.”

– *Community Collaborator*

Data ownership and dissemination of the results varied. Some of the projects agreed to co-own the data between the community group and the academic researcher. In other cases, the academic researcher maintained ownership of the data and the community group kept a product, such as a workbook, that was developed during the study.

Many of the collaborations did not have explicit agreements for the dissemination of study results. They did not discuss in advance questions such as whether the focus would be community or conference presentations, or published articles, and if articles were published, who would be listed as co-authors. For the most part, the academic partner developed the article and/or presentation and the community partner reviewed the work and gave input. Some teams worked more closely than others. One academic collaborator described a creative way they presented data to the community:

“One thing that came across quite clearly from the community was that so many researchers come into the community and research them but don’t come back to them with the results. We heard that a lot. One strategy that we have now is to make special community-based presentations. We also make sure the community knows that they have access to the research institution and the community-based organization and the data. If they want to do some research on their own they have that opportunity.”

– *Academic Collaborator*

VI. RECOMMENDATIONS

We asked respondents to identify problems they had in applying for, conducting, or reporting to the CBCRP about the research funded with the CRC Awards. We also asked them to make suggestions about what the CBCRP could do to help solve the problems they identified. The following describes the problems identified, suggested solutions, and recommendations to the CBCRP.

1. Grant awards (both Pilot and Full) should be larger.

In general, those interviewed felt that it costs more to work in collaboration with the community. More people have to be paid, study development takes longer, and there are often multiple program or administrative sites. Conducting research at community-based sites that lack the technology of university labs may also increase costs and compromise research quality if the funding is inadequate, as evidenced from this quote.

“At the University, when they tape groups they have a room that has several cameras shooting from several angles already set up in the room. We had to hire a camera person to come in. We ended up having to have a U shape rather than a circle so the video person could move around. It changed the dynamics.”

– *Community Collaborator*

Several researchers noted that in certain areas (the Bay Area, the Los Angeles area) there are so many breast cancer studies going on that participant recruitment was more difficult and took longer. Also, one researcher mentioned that she felt the grant amounts are below those made by comparable funders.

Community organizations were forced to deal with unintended financial consequences of their participation in the research project. Administrative costs, such as computers and staff time, were often not adequately considered or reimbursed (see point 7 below). Research projects that were based on service programs (retreats, support groups, workbooks) create a desire by clients for the service that often extends beyond the research funding period. Community organizations cannot always meet this need after the research funding has ended.

2. The CBCRP should increase support for the development of partnerships.

Several respondents suggested that community groups need more support in the beginning of the process. One idea was preliminary funding to help build trust between potential community and traditional research collaborators. Some respondents were confused about the Pilot Awards. They felt the wording of the application implied that they could apply for funding to begin developing a relationship, not that they had to start collecting data right away. Another suggestion was that the CBCRP offer nonprofits smaller planning grants to help them get to the point where they can apply for a Pilot Award. Another suggestion was for the CBCRP to hold interactive training workshops at the community level to help the community look at their questions and to give suggestions about what is researchable.

The trainings I went to for CBCRP and the tobacco research project were talking heads assuming a certain level of research knowledge.”

– *Community Collaborator.*

The limited available funding, the time required to fully work with the community, lack of support from their academic institutions, and lack of familiarity with the CRC awards all limit academic researchers' participation. Some suggestions for things the CBCRP can do to encourage more academic researchers to participate in the CRCs included:

- Adding a funding mechanism that pairs a junior academic researcher with a more senior one
- Holding meetings publicizing the CRC at academic institutions and during health research conferences
- Making suggestions about where to publish articles and give presentations on CRC research
- Developing a list of researchers who are interested in community research projects, along with including evaluations from community members who they have previously worked with them

3. The CBCRP needs to get grant awards to recipients in a more timely manner.

If the Pilot Award team is to move smoothly into the application for a full award, pilot data is needed by December. This makes the July 1 start date for the Pilot Award a priority. However, grant awards are announced just one to two months before the project is to begin. Funding often comes after the project's start date, sometimes as late as September. This delay in funding hurts the project as well as the nonprofit organization partner. Several community partners felt it was important to be the fiscal agent, as a means to achieve a more balanced power relationship with the academic researcher. But it is hard for nonprofit organizations to be fiscal agents, because they can not “float” funding for the study until the grant award is received.

“After we were told that we received the pilot grant, the actual receiving the money was a little vague. It was stressful on me because I felt that it was on me to get the money. I remember having a hard time getting an answer on when the money would come in and in what form. I remember stressing out that if the money didn't come I would have to pay for it myself.”

– *Community Collaborator*

4. The CBCRP should change the application timing.

Even if funds can be delivered in a more timely manner, the timing of progression from the Pilot Award to the Full Award also needs adjustment. Currently, in order to put together a competitive Full Award application, the research team needs pilot data within six months of the Pilot Award start date. If the team decides not to submit an application for the Full Award during their Pilot project, funding will lapse for up to a year between the end of the Pilot project and the potential beginning of the next Full Award period. This would lead to the dismantling of the team, because each partner would have to seek funding from other funding sources for other projects. Academic researchers, in particular, would then be pulled into other projects and not be able to rejoin the team. Suggestions for dealing with this issue included expanding Pilot Awards from the current 12 months to a higher award for 16 months, or adding a third type of award, possibly a research proposal development award, that would be a bridge between the Pilot and Full Awards.

5. The CBCRP should hold more meetings with more attendees.

Several community groups wished they had had more funding to bring more of their community members to the CBCRP's research symposium, held every two years. Some community members also felt that they could have benefited from meetings for all CRC research teams throughout the year. The community participants are at a disadvantage, not knowing as much about the world of research as the academics. While they learned a great deal in completing their studies, they felt more sharing between the teams would have been an improvement. Topics they suggested for these meetings include: contract requirements and reporting, solving methodology problems, and sharing ideas about where to publish. One community collaborator shared confusion about the reporting requirements:

“Much of what I have difficulty with is simply the unfamiliarity with the bureaucracy in the reporting and responding. There is a midyear report that came up that we still don't know what it means!”

– *Community Collaborator*

6. The CBCRP should take a more active role in supporting and advocating for community participation in research.

The CBCRP is inviting these research collaborations and should know that the community is going to be, in some ways, the more vulnerable party in the power dynamics they develop working with academic researchers. Additionally, the CBCRP needs to educate community groups, and not assume that community groups understand the rules and procedures (even if they are written down somewhere). For example, several community groups had no idea that they could include funding for indirect costs in their budgets. The assumption in the nonprofit community is that only the fiscal agent receives funding for indirect costs. Several organizations could have benefited from receiving funding of indirect costs. But even those community organizations that knew the grant award would pay for indirect costs didn't have the skill to figure out what to charge.

“We found as the project grew that there were costs that we weren’t aware of. It would have been helpful if CBCRP could provide some awareness of what to expect on indirect costs. They are funding it but you just need to know what to ask for.”

– *Community Collaborator*

Others had no idea that the funding could actually be flexible and that they could request no-cost extensions. One community member felt that if CBCRP staff called projects throughout the year, community-based researchers would feel more comfortable calling the staff with questions (see Point 8, below).

One researcher felt that the CRC program is trying to fit the community into a research structure rather than the other way around. It’s a conceptual shift. For example, several community groups felt demoralized by the funding rejections they received from the CBCRP reviewers. The harsh style of the criticism might well be understood within the context of the research milieu, but it is not typical for nonprofits. One organization did not re-apply because they felt the harshness of the criticism was the CBCRP’s way of telling them they didn’t have a chance of getting funding. Another community group had a member who was a researcher, so she was able to interpret the criticism and explain that the harsh language was not a condemnation of the organization. She commented:

“Reviewing the criticism of the first draft was hard. People felt like it was hard to hear what was being said. I was there and was able to let them know that it was how it happened. If I weren’t there they would have been really demoralized. CBCRP should know that that type of critique has a different impact on a community. Women with breast cancer have already been hit hard. I believe the criticism could have been more supportive and less harsh.”

– *Community Collaborator*

7. The CBCRP should improve and increase communication with researchers.

Both community and traditional researchers requested that the CBCRP staff improve and increase communication. Examples of poor communication were late notices for award letters, addresses not being changed after repeated requests, slow responses to questions, and no communication about deadlines and missing reports, followed by a letter that said, “Get this in or else.” Regular phone calls from CBCRP staff could help to establish a clear line of communication.

Better communication would be especially helpful during the application process and prior to finalizing the contract. Many community groups who have not participated in this level of research are not familiar with making necessary decisions such as who should be the fiscal agent and how to think through questions that arise in the development of the budget. Nonprofit organizations are accustomed to receiving funds with, or shortly after, a letter of award from a foundation. Community groups often don’t know the required process for finalizing contracts and receiving funding. Community research partners are also somewhat reluctant about being completely open with CBCRP staff, for fear that the funding will be removed if they say something they shouldn’t.

8. The CBCRP should ensure that partnerships are true collaborations.

Some of those interviewed didn’t fully understand that collaborative research is time consuming and requires active participation from all parties to ensure full collaboration. Interviewees said that the time required, and the actual or feared conflicts, make this type of research less appealing to community members and academic researchers alike.

The CBCRP applications and written materials are geared toward the perspective of a research scientist. Even a community researcher may perceive the materials as playing down the importance of community involvement. For instance, the CBCRP applications force the community collaborator to choose one co-

principle investigator, even if the community partners are planning to act as a committee or group. The biographical information requested is also heavily slanted toward academic history, and the forms give minimal direction for applicants to elucidate their community involvement. The forms should make suggestions about the number, type, and structure of letters of support that applicants should include.

The CBCRP's report forms do not ask specifically for clear documentation of community involvement. In fact, several of the community collaborators had minimal contact with their own organization, let alone the larger community, about the research projects. Application materials and report forms should require a clear description of advisory board meetings, meetings held in the community, contacts made with the community, and other methods the collaboration plans to use for community input.

In addition, the CBCRP could identify key people in a community and get information from them about whether they've been involved in the project or not. Some of the suggestions made in point 7, above, for additional meetings, and for funding for more individuals to attend the meetings, could also help nurture and guide the collaborations.

VII. SUGGESTIONS FOR SUCCESSFUL COLLABORATIONS

1. Expect some give and take

Many of the staff interviewed felt that both the research and the community collaborators need to be willing to “give and take.” Partners must be willing to listen to each other. It’s a time consuming relationship of learning from each other and developing sensitivity, sometimes going beyond the research project itself.

“I had no experience with the community when I started this research. I think, with all modesty, I’m now well accepted by the community. I’m involved in the community besides the research. I take part in the cultural activities. I show a presence.”

– Academic Collaborator

2. Community collaborators should have a clear idea of the benefits of doing research.

The community needs to ask what they will get from being involved in the research project. If the answer is “increase our knowledge,” that may not be enough for the effort required. Most of the community collaborators we interviewed gave examples of advantages of working with academic researchers. These included the following:

- Gaining academic researchers’ help and expertise in answering community members’ questions
- Being able to conduct research to support the need for community services
- Gaining prestige nationally with the scientific community
- Having access to scientists with whom community organizations can work on other projects and consult about questions regarding other research/medical issues

3. Academic researchers should understand the costs and benefits of doing collaborative research with the community.

Participatory research can be a slower research process than traditional research. If the community has to delay the project, the academic researcher must respect that and wait for the community to be able to participate. The researcher can’t jump to another community member or organization in order to keep the research going (as researchers sometimes can in non-participatory community-based research). Some academic collaborators said that participatory research can be “academic suicide.” It may slow or destroy their efforts for tenure. However, there are also advantages to working collaboratively with the community. The community has great ideas that an outside researcher wouldn’t think of. In addition, when the community is involved and actively making decisions on what is to be researched, the community has a stronger commitment to the study.

VIII. CONCLUSION

The CBCRP CRC awards have given communities of women affected by breast cancer power to formulate and initiate research projects addressing questions of concern to them. The CBCRP needs to do more to ensure that community members have the training, support, and information they need to participate as equal partners in the execution of the research and the analysis and dissemination of results. Financial constraints and the timing of the various grant awards also raise significant barriers to participation for even the most committed researcher. These should be addressed to support researchers interested in working collaboratively with communities.

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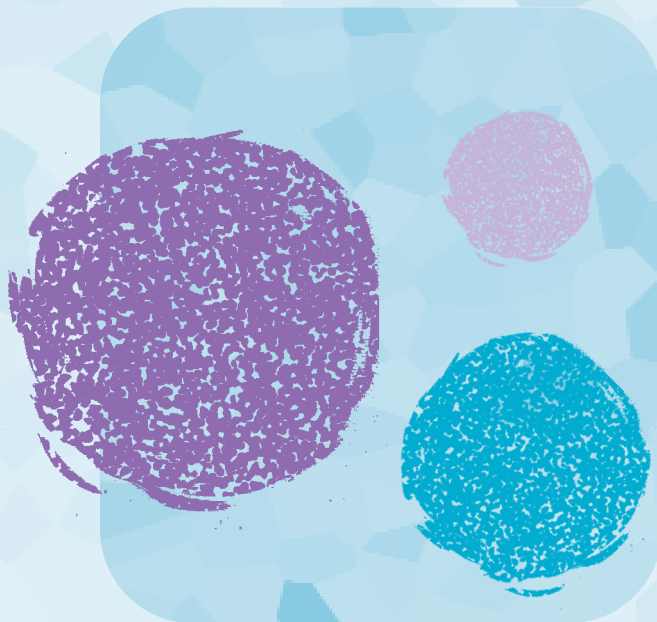
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The California Breast Cancer Research Program Community Research Collaboration Awards Evaluation

INTERVIEW QUESTIONNAIRE

FOR COMMUNITY AND ACADEMIC RESEARCHERS WHO RECEIVED FUNDING

- 1) Who is the target community in your research (define geographic and socio-cultural factors)?
- 2) What was the chronology of events, discussions, and meetings which culminated in the research proposal (i.e. did the impetus for the research come from the defined community or the researcher?)
- 3) What involvement did members of the target community have in the research proposal and implementation?
- 4) What effects (both positive and negative) do you think this research will have on the target community?
- 5) Is there an “action” component of the research for the community (i.e. is the gathering of information explicitly connected to some form of social change the community is interested in creating?)
- 6) What level of knowledge did the community PI have in research methods prior to the beginning of the project? Has that changed?
- 7) What level of knowledge did the research PI have of the community prior to the beginning of the project? Has that changed?
- 8) In what ways is the target community involved in the interpretation or analysis of the research results?
- 9) Are there explicit agreements between the community PI and the research PI with regards to resolving differences, ownership of the research data, and dissemination of the results?
- 10) Can you identify any problems you had in applying for, conducting, or reporting on the research that the research funder could possibly help with?
- 11) The purpose of this grant is community/researcher collaboration. Did you see a difference in this type of research from community-based research you’ve done in the past?



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