

Can the Women Most Affected by Breast Cancer Be Equal Partners in Designing and Conducting Breast Cancer Research?

EXECUTIVE SUMMARY

METHODS

The CBCRP contracted with the consulting firm Marj Plumb and Associates to evaluate 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 invited 31 current and past recipients of the CRC awards (representing 16 projects) as well as to 25 applicants who did not receive funding to take part in the evaluation. We conducted a total of 17 telephone interviews, 15 with current or past award recipients, representing nine projects and two with researchers who had unsuccessfully applied for funding. The interviews lasted 45-60 minutes. We also reviewed all of the grant applications and progress reports from the nine funded grant proposals associated with the 15 people we interviewed who had received CRC Awards.

CONCLUSION

The CBCRP has succeeded in making it possible for women affected by breast cancer to design and conduct research on the disease in collaboration with experienced research scientists. By making the changes in the research program suggested in the "Areas for Improvement" section above, the CBCRP can stimulate more of this type of research and make it possible for more women affected by breast cancer to collaborate on research as truly equal partners.

FOR MORE INFORMATION

For a free copy of the complete evaluation report, September 2001, Community Research Collaboration Awards, Report on the Evaluation & Capacity Expansion Project, please contact the California Breast Cancer Research Program or visit our web site.

Research Scientists and Members of Communities Affected by Breast Cancer are invited to request a copy of the current Call for Applications for Community Research Collaboration Awards, available free from the California Breast Cancer Research Program or on our web site.

Staff Members of Research Funding Agencies interested in funding community-researcher partnerships for their own program are invited to contact the CBCRP for more information.

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ABOUT THE CALIFORNIA BREAST CANCER RESEARCH PROGRAM'S COMMUNITY RESEARCH COLLABORATION (CRC) AWARDS

The California Breast Cancer Research Program (BCRP) is the largest state-funded breast cancer research effort in the nation. Breast cancer advocates played a leading role in passing the 1993 legislation that established the program. The CBCRP is under the administration of the University of California. The Community Research Collaboration (CRC) Awards, developed in 1997, 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, community clinics, organizations serving women with breast cancer, or organizations serving communities of women affected by the disease) and research scientists. 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. Between 1997 and 2001, CBCRP funded 22 collaborative projects for a total of nearly \$10 million.

CRC FUNDED AWARDS AND RESEARCH TEAMS

1997 PILOT AWARDS

"A Community-Based Workbook for Helping Rural Cancer Patients"
Sierra Nevada Memorial Hospital Cancer Center & Stanford University

"Increasing Annual Recall in State Early Detection Programs"
CHG Foundation & San Diego State University Foundation

"Breast Cancer Risk Factors: Lesbian & Heterosexual Women"
Lyon Martin Women's Health Services & University of California, San Francisco

"The Efficacy of a Retreat for Low-Income Women with Breast Cancer"
Charlotte Maxwell Complementary Clinic & California Pacific Medical Center Research Institute

"Breast Screening Program in the Hmong American Community"
University of California, Los Angeles & Orange County Asian & Pacific Islander Health Alliance

1998 PILOT AWARDS

"Marin County Breast Cancer Study of Adolescent Risk Factors"
Marin Breast Cancer Watch & University of California, San Francisco

"Study of Inadequate Follow-up of Mammography Abnormalities"
Bay View-Hunter's Point Health Care Task Force, San Francisco Department of Public Health & University of California, San Francisco

1998 FULL AWARDS
"Samoans and Breast Cancer: Evaluating a Theory-based Program"
National Office of Samoan Affairs & University of California, Irvine

"Breast Cancer Risk Factors: Lesbian and Heterosexual Women"
Lyon Martin Women's Health Services & University of California, San Francisco

"Increasing Breast Health Access for Women With Disabilities"
Alta Bates Foundation & Northern California Cancer Center

"Do Community Cancer Support Groups Reduce Physiologic Stress?"
The Wellness Community-National & Stanford University

1999 PILOT AWARD
"Returning to Work and Quality of Life after Breast Cancer"
University of California, San Francisco & Women's Cancer Resource Center

1999 FULL AWARDS
"Marin County Breast Cancer Study of Adolescent Risk Factors"
Marin Breast Cancer Watch & University of California, San Francisco

"Breast Health Project for Hmong Women and Men"
University of California, Los Angeles & Orange County Asian & Pacific Islander Health Alliance

"A Support Group Alternative for Rural and Isolated Women"
Stanford University & Sierra College

2000 PILOT AWARD
"Does a Peer Navigator Improve Quality of Life at Diagnosis?"
WomenCare & Stanford University

2001 PILOT AWARDS

"Breast Cancer Prevention and Control Among Deaf Women"
University of California, Los Angeles & Greater Los Angeles Council on Deafness, Inc.

"Efficacy of a Community Program in Increasing Access to STAR"
University of California, Los Angeles & Association of Black Women Physicians

2001 FULL AWARDS
"Effectiveness of Internet vs. Face to Face Support Groups"
University of California, San Francisco & The Wellness Community-National

"Return to Work after Breast Cancer Surgery"
University of California, San Francisco & Women's Cancer Resource Center

"A Network-Based Intervention for Chamorros in Southern CA"
Guam Communications Network, Inc. & University of California, Irvine

"Does a Peer Navigator Improve Quality of Life at Diagnosis?"
WomenCare & Stanford University



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MAJOR FINDINGS

The CBCRP CRC Awards have empowered the women most affected by breast cancer to participate as full partners in the research process. Making communities affected by breast cancer equal partners in research opens up new questions that might not otherwise get studied. Because collaborative research can be time-consuming and complex, the program can be improved to make it more user-friendly for both research scientists and women affected by breast cancer who are new to research.

Successes:

- 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 members who collaborated on the research were breast cancer survivors.
- II. The CBCRP supported several research partnerships in re-designing their studies and re-application. This is a much needed service component when introducing non-research communities into the research milieu.
- III. The CBCRP 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.

Spurring Research with Under-Studied Population Groups

The CBCRP's Community Research Collaboration Awards spurred breast cancer research with populations not often so included, such as: ① disabled women, ② rural women, ③ lesbians, ④ women of Samoan heritage, ⑤ women of Korean heritage, ⑥ women of Hmong heritage, ⑦ immigrant women from Guam, ⑧ deaf and hard-of-hearing women.

Areas for Improvement:

- I. Community groups are at a distinct disadvantage when trying to understand the policies and procedures of a research funding institution. In the nine studies evaluated, community groups were not able to consistently participate as truly equal partners, often due to the lack of information and experience with research and with research funding procedures. The CBCRP should take the initiative to increase communication with the funded partnerships including creating more opportunities for the teams collaborating on research 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.
- IV. Grant awards should be larger to accommodate additional costs associated with community collaboration research.

OTHER FINDINGS

Goal: Empowering women affected by breast cancer to initiate research projects that concern them.

Finding: Of the nine projects evaluated, members of a community affected by breast cancer initiated the research and actively sought out academic collaborators in six of the research projects. An academic researcher initiated one project; two teams had worked together before.

Goal: Community collaboration research should give communities tools they need to create social and political change.

Finding: All of the members of communities affected by breast cancer who collaborated on CRC research 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

Goal: Developing the research skills of women affected by breast cancer.

Findings:

- 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. 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.

- Many of the projects 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. Having some level of familiarity with medical terms and research concepts brought expertise to the collaboration. Some also expressed unintended positive effects on their clinical practices and lives.

Goal: Maximum participation of the community under study.

Finding: Although the research teams all included people who worked with or were members of the communities being studied, the research projects were weakest on wider community participation.

- Four out of nine projects included the community with activities such as community meetings; meeting with core groups of community members over an extended period of time; and having clients provide feedback on the proposal, research methods, and tools.
- Most of the teams discussed pulling together advisory groups to review the interpretation or analysis of the research results. Two teams felt that they didn't involve the community in the analysis as well as they should have. 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.

Goal: Sharing of power between academic and community researchers.

Finding:

- All projects had 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.

- Community partners that had more than one community member on the research team felt it balanced the power of the academic researcher, and, often, the academic institution. Those research teams who had disputes that were addressed within the study period succeeded in working out their differences, with one exception.
- Data ownership and dissemination of the results varied. In some of the projects the community group and the academic researcher co-owned the data. In others, the academic researcher maintained ownership of the data and the community group kept a product, such as a workbook, 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 academic 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.