

## ABSTRACT

Community-based, participatory research (CBPR) has emerged as a vital strategy for developing effective, culturally relevant health interventions. The COTC goals and activities within the Bay Area Breast Cancer and Environment Center and in the community are guided by the key principles contained in the following definition of CBPR.

Community-based participatory research is a collaborative approach to research that equally involves all partners—community members and scientists—in the research process and recognizes the unique strengths that each brings. Community-based, participatory research begins with a research topic of importance to the community with aim of combining research knowledge and community action to improve community health and eliminate health disparities.

The concept of community and community involvement is central to the successful implementation of CBPR. While there is a growing body of literature on CBPR and the strengths and challenges of building a collaborative partnership, there are few articles focused on the structures, processes and activities which promote early and sustained involvement of communities in the research process and foster long-term relationships between researchers and the communities they study.

This poster illustrates a conceptual framework that has guided the COTC's efforts to foster ongoing cross communication and dialogue between researchers, COTC members and the communities where the research is being done. Included in the framework are guiding principles and assumptions, process and sequence of activities and outcomes. We will highlight lessons learned in using a community-based participatory approach within the Center and in the community to enhance community involvement.

# Enhancing Community Involvement in the Research Process

## Bay Area Breast Cancer and Environment Research Center Community Outreach and Translation Core (COTC)

Janice Barlow, Marin Breast Cancer Watch; Fern Orenstein, Marin Breast Cancer Watch; Kathy Koblick, Marin County Department of Health and Human Services; Karen Goodson Pierce, Bayview Hunters Point Health and Environmental Assessment Task Force, San Francisco Department of Health; Ben Fraticelli, California Health Academy; Dr. Hope Rugo, Breast Oncology, UCSF Comprehensive Cancer Center; Carolene Marks, Breast SPORE Advocacy Core; Lori Low, The Breast Cancer Fund



## GUIDING PRINCIPLES and ASSUMPTIONS

## PROCESS AND ACTIVITIES

## OUTCOMES

## IMPACT

### Community involvement in the research process is facilitated through participation in Community-Based, Participatory Research (CBPR)

#### CBPR:

Involves community-researcher collaboration on all aspects of the research process from considering and developing the research questions, to designing the methodology, participating in the research activity, analyzing the results and disseminating the findings.

Ensures that research being done is relevant to community needs, strengthens the community's capacity to address health risks, provides useful tools for further evaluation and research and supports policy changes aimed at improving community health.

Provides opportunities for knowledge transfer from the community to the researcher about the community of interest, builds trust between researcher and community members and instills confidence that the research being done will be of benefit to the community.

Promotes shared decision making, information, resources, support, skills, capacity and power between and among researchers and the community in which the research is being done.

#### Community:

Use of the term "community" often fails to accurately reflect the many diverse types of communities, as well as differences within communities. Within any geographic area or demographic community, *there is no single community* that encompasses or represents the concerns and interests of everyone.

By exploring different meanings of community and using different approaches to involving communities, we can effectively develop a variety of community-specific models for translating the scientific research.

#### Community-based translation and dissemination of information:

Seeks to assure that communications from the Center are salient, relevant and culturally sensitive to diverse audiences.

Endeavors to design communication strategies that give people the information they want, how they want it, where and when they want it and in a way that is understandable.

Facilitates an understanding of the research process.

Recognizes that advances in breast cancer and environment research do not easily translate into behavioral, social or policy changes; however, researchers, public health professionals, health providers and communities can work collaboratively to translate findings into information tools and resources that can be applied to improve public health outcomes and eliminate health disparities.

### Creation of infrastructure reflecting principles of CBPR:

- Within the Bay Area Breast Cancer and Environment Center, researchers and members of the Community Outreach and Translational Core established a shared commitment to community-based participatory research principles. Two members of the COTC have been designated (as part of the original grant proposal) to be Community Co-Investigators on the two scientific projects, attend monthly meetings and facilitate the infusion of the community perspective into the design of the research protocol.
- Three Bay Area community meetings (San Francisco, Bay View Hunters Point, and Marin) were held to provide opportunities for project scientists, COTC members and community participants to share knowledge about the Center's activities and learn about community concerns and interests in relation to the role environmental factors may play in the development of breast cancer. At all three community meetings, attendees were given an opportunity to share their thoughts about specific environmental factors that contribute or are suspected to cause breast cancer.

### Partnership building:

- Maintained pre-existing partnerships in Marin and San Francisco while developing relationships with diverse community groups and community-based health leaders.
- Community meetings served as a forum for increasing awareness of the uniqueness of each community and for exchanging perspectives and concerns about environmental health and breast cancer.
- Included in all three community meetings were small group discussions identifying each community's strengths and assets for building and sustaining inter-community partnerships.
- Sponsored a community forum on "Critical Issues in Biomonitoring" in partnership with local environmental and breast cancer organizations, bringing together nationally recognized speakers from NIEHS Centers on Breast Cancer and Environment Centers, CDC, NHANES, California Department of Health and Human Services, California Environmental Health Investigators Branch, California Environmental Tracking Program, UC Berkeley and interested community-based breast cancer and environmental organizations.

### First year planning for community-based translation and dissemination:

- Used multiple communication channels to educate key audiences about the Center including TV, radio, print media, local events, informational presentations, organizational newsletters and educational materials (in English and Spanish).
- The three Bay Area community meetings were designed to solicit information on how best to keep communities informed of research findings, how to overcome barriers to participating in the Center's activities and how to successfully work with preteens.

- Developed a comprehensive mailing list of over 950 geographically diverse individuals (breast cancer advocates, researchers, public policy makers, health professionals, environmental organizations, breast cancer survivors and community members) who have indicated an interest in being kept informed of the Center's findings over the next six years.

- A summary and analysis of community input received at 3 community meetings. Input was collected specifically through small discussion groups focusing on; community concerns about the environment, identifying community's strengths and assets for building partnerships, suggestions for keeping the community informed, overcoming barriers to participation in the Center and successful ways of working with preteens. This valuable information will be used in future community-specific translational strategies.

- Infusion of the principals of CBPR into the research process of the Center within the first year.
- Increased knowledge within target communities about the research Centers.
- Expansion of partnerships within communities and between researchers and community advocates involved in the project.

- "Critical Issues in Biomonitoring" presented up-to-date information about the art and science of biomonitoring and discussed the significant contribution biomonitoring will play in the Center's research on the role environmental factors play in the development of breast cancer.

- Evaluation results demonstrated the extent attendees and speakers were highly satisfied *with a community forum mode for translating research and technical information, for communicating risk and for eliciting community involvement.*

- **A broader and stronger community capacity for advancing research into the environmental causes of breast cancer.**
- **A solid foundation for developing and sustaining community involvement in the Center's projects.**
- **Empowered communities and individuals who know they can, either personally or as a part of a community effort, make a significant contribution to the scientific process.**



## CONTEXTUAL CONDITIONS and CHALLENGES

- Establishing trust
- Gaining access to communities
- Varying level of commitment among researchers and advocates
- Time consuming process
- Creating a sustainable infrastructure
- Creating mutually beneficial (agenda/process) for ongoing COTC involvement
- Infusing principles of CBPR within basic science protocols
- Adequate funding to implement processes to enhance CBPR