



CALIFORNIA
Breast
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Research
PROGRAM

Introduction to Community- Based Participatory Research

& the CBCRP CRC Awards

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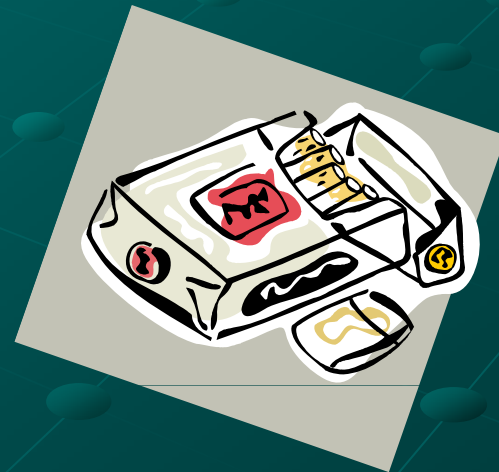
Outline of Presentation

- California Breast Cancer Research Program & Community Research Collaboration awards
- Community-Based Participatory Research
- Building and Sustaining a Collaboration



Creation of CBCRP

- Passage of The Breast Cancer Act of 1993
- Funding from a 2 cent per pack cigarette surtax, which generates approximately \$38 million per year
 - 45% California Breast Cancer Research Program
 - 50% Breast Cancer Early Detection Program
 - 5% California Cancer Registry





CBCRP Priorities

1. The Community Impact of Breast Cancer: The Social Context
2. Etiology and Prevention: Finding the Underlying Causes
3. Biology of the Breast Cell: The Basic Science of the Disease
4. Detection, Prognosis, and Treatment: Delivering Clinical Solutions

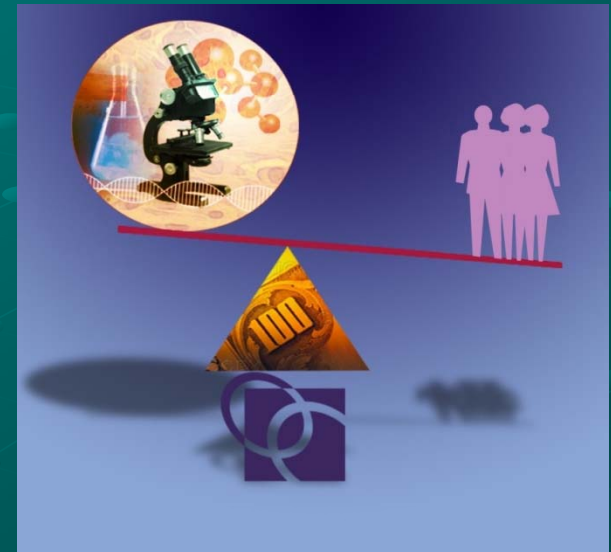
<http://www.cbcrp.org/research/>



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CBCRP CRC Awards

- Based on community- based participatory research (CBPR)
- Addressing breast cancer needs of interest to community members
- Since 1997 CBCRP has awarded more than \$16 million to 61 collaborative projects



...the CRC Awards

● Pilot Award

- 18 months
- \$150,000 plus indirect costs

● Full Award

- 3 years
- \$600,000 plus indirect costs



- \$2 million annual set-aside for CRC Awards
- Historically high funding rates, 15-50% of applications funded

CRC Requirements

- Solid research plan with compelling research question
- Equal CBPR partnership between community members and research scientists to:
 - Identify the research question
 - Develop the research plan
 - Carry out the research
 - Interpret the results
 - Disseminate results





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What have we funded?

UCLA and the Breast Cancer Early Detection Program

- Focus groups with Latina breast cancer survivors to explore their knowledge, attitudes, beliefs, and experiences with breast cancer care after completion of primary treatment, perceived barriers and facilitators to receipt of care.

UC Berkeley and Afghan Coalition

- Face-to-face interviews with 50 first generation immigrant Afghan women to learn more about the existing barriers in access and utilization of breast health care services from the women's personal point of view.

Northern Sierra Rural Health Network & Stanford University

- To discover if women with breast cancer in rural communities will find a support group format utilizing videoconferencing acceptable and rewarding and will they report a greater sense of emotional and informational support, and less depression and traumatic stress?

Young Moms with Breast Cancer and Stanford University

- Phase II clinical trial of the GnRH-analogue triptorelin before and during breast cancer chemotherapy in 32 women aged 35-44.

Funded Projects Focus on Diverse Populations of Women

- Disabled
- Lesbians
- Rural
- African American
- Latina
- Samoan
- Korean
- Hmong
- Guam
- Afghan
- Latina women with diabetes
- Vietnamese nail salon workers
- Women at the end of life
- Native American
- Southeast Asian
- Slavic
- Thai
- Young Mothers
- Deaf and hard-of-hearing



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What is Community- based Participatory Research?

What is CBPR?

1. Collaboration of an identified community with an academic or trained researcher
2. in the conduct of research techniques to answer questions of interest to the community,
3. for the purposes of informing the community, taking some action, or creating some change.

Green, et al 1996





Limits of Traditional Research

● Despite advances

- Limited to explain why certain outcomes occur
- Limited in ability to translate research to programs
- Over-emphasize individual level risk rather than population level in context to social issues
- Controls variables to focus on single item of exposure rather than using multiple, inter-related factors
- Direct detached observation as only source of knowing

Leung, M. W., et al (2004)

Benefits of CBPR

- It Benefits the **Community**
 - Answers important questions, develops research & evaluation skills, funds community, builds capacity, provides data for advocacy & change
- It Benefits the **Researcher**
 - Enables ethical access to communities, uses community knowledge to create more relevant research, research is used for change, provides data for publications, funds researcher
- It Improves the **Research**
 - Methodology and analysis strengthened with community input, results (data) more likely to be disseminated and used



CRC Evaluation

- The characteristics MOST often seen among successful teams were:
 - Shared power throughout project
 - Shared question development
 - Shared conducting study
 - Shared methods planning
 - Had greater community involvement
 - Had greater board/staff involvement



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Developing Your Collaboration



Who is the Community?

“Any group of individuals sharing a **given interest**; this definition includes cultural, social, political, health, and economic issues that may link together individuals who may or may not share a particular geographic association. This definition includes the traditional concept of community as a geographically distinct entity.”

George et al (1998-99)

Role of Researcher

● The Initiator

- Researcher generates questions, seeks out community for participation in study

● The Consultant

- Contracted by the community to conduct a study, or
- Provides consultation to the community conducting research on its' own

● The Collaborator

- Truly equal relationship throughout study that is conducted jointly

Finding a Partner



- Finding a **Researcher**
 - Ask Breast Cancer Providers, other Advocates, Universities
 - Lit Search, Google, University Websites
- Finding a **Community Partner**
 - Ask other researchers, breast cancer providers, survivors
 - Organizations websites, newsletters, events





"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."

— Community Member





What is Collaboration?

1. exchanging information,
2. altering individual interests & plans,
3. sharing resources,
4. building the capacity of each other.

Collaborative Environment

- Members have a history of collaboration or cooperation
- Members are seen as legitimate leaders in their field or with their community
- Collaborative organizations are healthy, well-functioning, stable
- Members are self-reflective and good communicators
- Partners have time to collaborate
- Partners work styles are compatible



“[Our research partner] comes with the premise that the community knows best and the **community are the experts**. It wasn't, 'I'm the researcher and I'm going to tell you what to do and you're going to do this' it was more like, 'well what do you think we should do?', and 'what's going on?', or 'what would you develop?' or 'how can I help?'

- CRC Community Partner

Research Question

- What do you want to know?
 - **Brainstorm** areas of concern
 - Write into question format
 - **Prioritize** issues
 - How important is it to answer this question?
 - **Determine Feasibility**
 - Can the question be answered with a sound research proposal?



Difference Between Research and Evaluation

- Evaluation – Do the clients like the program? How many clients participated in the program?
- Research – Does the program have an effect? What is the size of the effect? What components are responsible for the effect? Is this generalizable?



Resources

● Websites:

- California Breast Cancer Research Program
www.cabreastcancer.org/community/
- Loka Institute www.loka.org
- Community-Campus Partnership for Health
<http://www.ccph.info/>

● Journal:

- Progress in Community Health Partnerships
<http://pchp.press.jhu.edu>

● Books:

- “Community-Based Participatory Research for Health” by M. Minkler and N. Wallerstein
- “Methods in community-based participatory research for health” by B. Israel, et al

CRC Awards Timeline



- August 2010 *Call for Applications posted*
- September 2010 *Application Materials posted*
- September 2010 *Application Materials webinar*
- **October 14, 2010** *Optional Research Plan Review*
- **February 24, 2011** **Application due**
- April – May, 2011 *Peer review of Applications*
- June 2011 *Advisory Council Programmatic Review*
- June 2011 *Funding announced*
- August 2011 *Awards begin*



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Assistance Is Available

**For more information about the CRC Awards,
technical assistance, or to request a speaker
at your conference or meeting:**

Contact:

California Breast Cancer Research Program

Toll-Free: (888) 313-BCRP

CRCinfo@cabreastcancer.org

For More Information:

www.cbcrp.org



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Thank you!



Questions?