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

2. Etiology and Prevention: Finding the Underlying Causes
4. Detection, Prognosis, and Treatment: Delivering Clinical Solutions

http://www.cbcrp.org/research/
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
What have we funded?
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.
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.
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
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 then 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

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

Israel et al 2001
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

Plumb et al 2005
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

Stoecker 2003
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/](http://www.cabreastcancer.org/community/)
- Loka Institute [www.loka.org](http://www.loka.org)
- Community-Campus Partnership for Health
  [http://www.ccph.info/](http://www.ccph.info/)

Journal:
- Progress in Community Health Partnerships
  [http://pchp.press.jhu.edu](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
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.cbcrrp.org
Thank you!

Questions?