



Introduction to Community Research Collaboration Awards

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1

Outline of Presentation

- Background on the California Breast Cancer Research Program
- Understanding collaborative research and finding a partner
- Important elements of a research plan



2

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



3

CBCRP Priorities

- 1 **The Community Impact of Breast Cancer: The Social Context**
 - Health Policy and Health Services: Better Serving Women's Needs
 - Socio cultural, Behavioral, and Psychological Issues Relevant to Breast Cancer: The Human Side
 - Disparities: Eliminating the Unequal Burden of Breast Cancer
- 2 **Etiology and Prevention: Finding the Underlying Causes**
 - Etiology: The Role of Environment and Lifestyle
 - Prevention and Risk Reduction: Ending the Danger of Breast Cancer
- 3 **Biology of the Breast Cell: The Basic Science of the Disease**
 - Biology of the Normal Breast: The Starting Point
 - Pathogenesis: Understanding the Disease
- 4 **Detection, Prognosis, and Treatment: Delivering Clinical Solutions**
 - Imaging, Biomarkers, and Molecular Pathology: Improving Detection and Diagnosis
 - Innovative Treatment Modalities: Search for a Cure

4

CBCRP Funding Mechanisms

- **Innovative Developmental and Exploratory Award (IDEA):**
High-risk/high-reward projects up to \$150,000 direct costs for up to 18-months.
- **IDEA-competitive renewal:**
Up to \$250,000 direct costs for up to 2-years.
- **Translational Research:**
For projects that overcome barriers and put prior research knowledge to practical use in the patient or community setting. Up to \$750,000 direct costs for up to 3-years.
- **Postdoctoral Fellowship:**
For career development-oriented training under a breast cancer research mentor. Up to \$135,000 for up to 3-years.
- **Dissertation:**
For the completion of dissertation research by masters or doctoral candidates. Up to \$38,000/yr for up to 2-years (1-year for Masters level).
- **Joining Forces Conference:**
Supports a conference, symposium, retreat, or other meeting to stimulate new ideas and collaborations. Up to \$25,000.

And...

5

...the CRC Awards

- **Pilot Award**
 - 18 months
 - \$150,000 plus indirect costs
- **Full Award**
 - 3 years
 - \$600,000 plus indirect costs



6

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



7

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 60 collaborative projects



8

What is Community-based Participatory Research?

CBPR requires the **collaboration** of an identified community with an academic or trained researcher in the conduct of **research** techniques to answer questions of interest to the community, for the purposes of informing the community, taking some **action**, or creating some change.



Green, et al 1996

9

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

10

Timeline



- | | |
|-------------------|--|
| • May-June 2009 | Outreach webinars and presentations |
| • May-August 2009 | Find partners, begin project development |
| • August 2009 | Call for applications posted |
| • September 2009 | Application materials webinar |
| • November 2009 | Online application system webinar |
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| • May 2010 | Advisory council programmatic review |
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| • July 2010 | Awards begin |

11

Award Process

- Awards are contingent on
 - IRB approval
 - Any changes recommended by review
 - Other administrative issues (overhead issues, possible grant duplication)
- Funds disbursed annually
- Annual progress reports and final report required
- 20% funding of last year of grant disbursed after all reports received and accepted (non-UC budgets)



12

Overview of 2008 Funding

Award Type	Number of Applications	Grants Funded (success rate)	Amount Awarded	Percentage of total funding
Dissertation	32	11 (34%)	\$759,909	9.4%
Postdoctoral Fellowship	48	6 (12.5%)	\$745,956	9.2%
IDEA	82	11 (13%)	\$2,284,111	28.2%
IDEA-Competitive Renewal	10	2 (20%)	\$621,906	7.7%
Translational	9	2 (22%)	\$1,553,111	19.2%
CRC Pilot Award	8	2 (25%)	\$386,796	4.8%
CRC Full Award	7	4 (57%)	\$1,645,686	20.3%
Joining Forces Conference	4	4 (100%)	\$89,919	1.1%

13

Examples of Funded Projects

- **The Mendocino Cancer Resource Center and UCSF** are studying whether a treatment decision-making aid previously used in an urban hospital setting can succeed as a telephone intervention for a diverse rural community.
- **The Northern California Cancer Center and Asian Health Services** are collecting information on Vietnamese American women working in nail salons in Alameda County. The study examines health care access and utilization, behaviors relevant to breast cancer risk such as smoking and exercise, and occupational exposures to substances that may cause breast cancer.
- **UCSF and the Charlotte Maxwell Complementary Clinic** are examining end-of-life issues from the viewpoints of underserved women with terminal breast cancer, their providers, and informal caregivers.

14

Important Elements of a Research Plan

15

Difference Between Research and Evaluation

- Evaluation – Is the program effective? Do the clients like the program?
- Research – Does the program have an effect? What is the size of the effect? What components are responsible for the effect?



16

Literature Review

- Is your research question overstudied or understudied? See funded grants:
 - <http://www.cancerportfolio.org>
 - <http://cdmrp.army.mil/bcrp/>
 - <http://komen.org/>
 - <http://www.cbcrp.org/>
 - <http://www.cancer.org>
- Literature search: www.pubmed.com
- How will the aims of your study add to the current knowledge of breast cancer?



17

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?



18

Research Design



- Descriptive or Experimental
 - In a descriptive study, no attempt is made to change behavior or conditions--you measure things as they are.
 - In an experimental study you take measurements, try some sort of intervention, then take measurements again to see what happened.



19

Hypothesis

What do you think you will find?



"Women with and without BC differ in their distributions of studied factors."

"Peer navigation will improve quality of life for BC patients if done at time of diagnosis by reducing emotional stress."

20

Conceptual Frameworks

Why do you think you'll find that?

Examples:

- Health Belief Model (Rosenstock)
 - People are more likely to comply with health information when:
 - they feel susceptible
 - they believe the consequences will be severe
 - they believe the benefits will outweigh the costs
 - and they can carry out the recommended action
- Transtheoretical Model for Change (Prochaska)
 - People will change if they follow these steps:
 - Pre-contemplation
 - Contemplation
 - Action
 - Maintenance



21

Types and Sources of Data

- Quantitative (i.e. numbers)

Surveys

Existing Databases

Bio markers (blood, urine, etc.)



- Qualitative (i.e. words)

Interviews

Focus Groups

Writings (journals, on-line communications)



- Mixed Methods (i.e. numbers and words)

22

Collecting Data

- Sample and Universe
 - Choose a sample of the universe that would tell you about the universe
 - Stratified sampling
 - Cluster sampling
 - Systemic sampling
- Timing is Everything
 - When to gather data, what kind of data to gather, what way to gather it?



23

Data Analysis Plan

- Gathering and cleaning data
 - Ensuring completeness
- Entering data into a system
 - Double entry to ensure accuracy
- Sorting data by assumptions
 - Testing data based on theoretical framework
- Interpretation of data
 - What does it all mean?



24

A Word About Randomized Control Studies

- Gold Standard Research
 - Provides best opportunity to state effect
 - Allows for control of selection bias
 - Cofounders are evenly distributed
- Concerns
 - Community needs and sensitivity regarding “no treatment” group
 - Public perception of CBO/service provider



25

Understanding Collaborative Research and Developing Your Partnership

26

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



27

"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



28

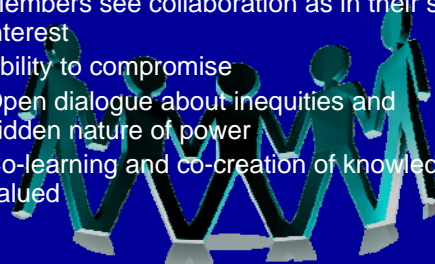
Interview Potential Partners

- What are each other's interests?
- Are the partners skills and experiences adequate for the project?
- Are the partners reputations strong within scientific field and/or community?
- Are your work styles compatible?
- Do you each have enough time?

29

Collaboration Characteristics

- Mutual respect, understanding, and trust
- Diverse cross section of members
- Members see collaboration as in their self-interest
- Ability to compromise
- Open dialogue about inequities and hidden nature of power
- Co-learning and co-creation of knowledge valued



30

“[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?'

- Community Member

31



Communication

- Take the time to meet in person as often as you can and in each other's locations.
- Plan for time in your meetings to discuss not only the research process but how things are going in your partnership.
- Discuss preferred communication – phone (home or work) or email (home or work)
- How will you deal with disappointment? Concerns? Confusions? Conflicts?

32

Clear Decision-Making

- Allow time for decision making
- Decide how decisions will be made
 - Who will be involved in the discussion?
 - Who will be consulted?
 - Who will make final decisions?
 - Who should be informed of decisions?



33

Involve Members of the Community

- Have deep organizational involvement
 - Staff
 - Board
 - Clients
 - Volunteers
- Include outside community members
 - As research team members
 - As reviewers of your materials
 - On a **real** Community Advisory Board



34

Discuss Finances

- How much money will your project cost?
- How will money be dispersed between the community partner and the academic partner?
- Begin investigating the capacity of each partner to manage research funding.
- What's important to you about how money is allocated and managed?



35

Data Ownership and Future Uses

- Who will own the data?
- Where will data be stored?
- Who will have access to it?
- How will data be used beyond the project phase?
- Who will own any products that are developed (such as survey tools, resources, training curriculum, etc.)?
- Who can give permission for others to use the data or products?



36

How will you Distribute Results?

- Who will be allowed to talk about the research, including to the community and to the media, while the study is ongoing?
- Where will you distribute the results and in what order or combination (peer-reviewed journals, community meetings or community newsletters)?
- Who will be responsible for writing the articles or preparing the presentations, who must sign off on it, and how will you deal with co-authorship?



37

Protection of Human Subjects

- What is important to both partners about protecting the participants in the research?
- Which IRB will you go to?
- How will you work with the IRB to secure both partners access to protected data?



38

Bumps Along the Road

- Maintaining balance of power and work throughout the study
- Community vs. scientific dissemination of results
- Unexpected or negative results
- Insufficient communication
- Turn-over of co-PI, project team and/or CBO leadership
- Institutional rules and regulations
- Lack of financial resources



39

How will you Handle Disagreements?

- A step-by-step process:
 - Talk through problems
 - Choose a mediator (facilitates communication)
 - Choose an arbitrator (makes decision)
- Ask CBCRP
 - To provide partnership TA



40

“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 Member



41

Develop a Partnership Agreement

- Decision-making
- Handling disagreements
- Data ownership and future uses
- Distribution of results
- PI and/or research team turn-over
- Finances



42

CBPR Resources

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

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44

Assistance Is Available

For more information about the CRC Awards, technical assistance (including finding a partner, feedback on research ideas, workshops, grantsmanship trainings) or to request a speaker at your conference or meeting:

Contact:

Katherine McKenzie, Ph.D.
 California Breast Cancer Research Program
 Phone: (510) 987-9884
 Fax: (510) 835-4740
 Toll-Free: (888) 313-BCRP
 Website: www.cbcrp.org
 CRCinfo@cabreastcancer.org

45

After the call...

- You'll receive an email with links
 - To the power point handout



- To a survey monkey evaluation

46

Thank you!



And good luck!

47

Q & A

48