

SPECTRUM OF COMMUNITY-BASED PARTICIPATORY RESEARCH

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THANKS!

- ◉ Cancer Prevention Institute of California
- ◉ Vietnamese Community Health Promotion Project, UCSF
- ◉ Vietnamese Reach for Health Coalition

- ◉ California Breast Cancer Research Program
 - Community Research Collaboration Awards
 - Pilot and Full Awards
 - \$2 million/year to CBPR teams

OBJECTIVES

- ◎ Upon Completion of this Presentation you will be able to:
 - ✓ Identify the spectrum, principles, benefits and challenges of CBPR
 - ✓ Describe the values and principles of CBPR
 - ✓ Identify the barriers and facilitating factors associated with CBPR
 - ✓ Describe the advantages of CBPR as an approach to research

WHAT IS CBPR?

- ◉ Equal partnership between community members and research scientists
- ◉ Partners work together to:
 - Identify the research question
 - Develop the research plan
 - Carry out the research
 - Interpret the results
 - Disseminate results

CBPR IS

“...a collaborative process that equitably involves all partners and recognizes their unique strengths. CBPR begins with a topic of importance to the community with the aim of combining knowledge and action for social change.”

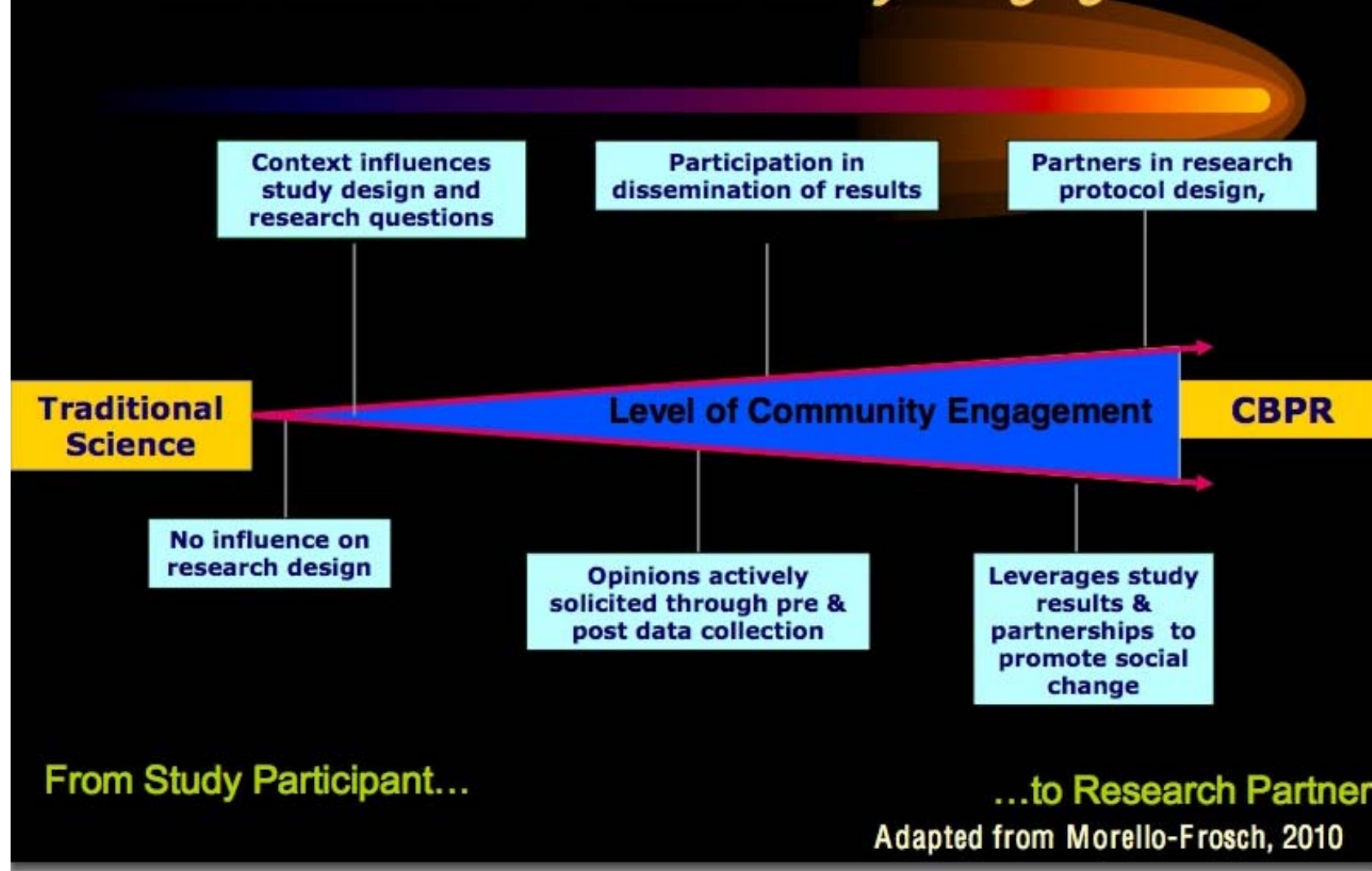
TALK IN PAIRS: WHAT MAKES COLLABORATIONS WORK?



PRINCIPLES



Continuum of Community Engagement



TRADITIONAL VS. CBPR

Traditional Research	Community-based Participatory Research
Outside Expert conducts research	Outside and Inside Experts conduct research
Expert defines what needs to be researched and how	Collectively decide focus of research and methods
Results may or may not be used to make changes in the community	Early buy-in from community increases impact of results
Capacity leaves with expert	Capacity is built two-way

WHY DO PARTICIPATORY RESEARCH?

- ◉ Dominant US/European research model was based on the theory that knowledge could only be gained through direct observation and experimentation, instrument and methodology rigor, statistical precision and replicability
 - Strong model for understanding population behaviors, risks, health care and prevention usage, and health status
 - Limited to explain the meaning of why certain outcomes occur and how to translate research into programs

Hall 1992 & Leung et al 2004

WHY DO CBPR?



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 production of knowledge
 - Methodology and analysis strengthened with community input, results (data) more likely to be disseminated and used

BREAST HEALTH PROJECT FOR HMONG WOMEN & MEN IN CALIFORNIA



MOST MEANINGFUL ASPECTS OF CBPR FOR COMMUNITIES OF COLOR

- ◆ Respect for community researchers and wisdom in the community
- ◆ Increase number of community researchers
- ◆ Community understands role of participant in research is “*Partnership*” and not getting “experimented on”
- ◆ *Data and publications* from the community
- ◆ *Funding to the community* to be able to address cancer prevention and control
- ◆ Increase in *cultural competent* resources
- ◆ Increase in *policies* regarding access to care
- ◆ Increase in recognition of *underserved communities and disparities* in health



“a practice that attempts to put the less powerful at the center of the knowledge process...”

Hall 1992

SIMPLY PUT...

Knowledge is Power!

BRAINSTORM: WHAT
QUESTIONS DO YOU HAVE
ABOUT THE HEALTH OF
YOUR COMMUNITY?



“We saw that women with cancer were having difficulty getting benefits, and dealing with housing and employment discrimination. We were wondering how come some women did really well and others didn't.”

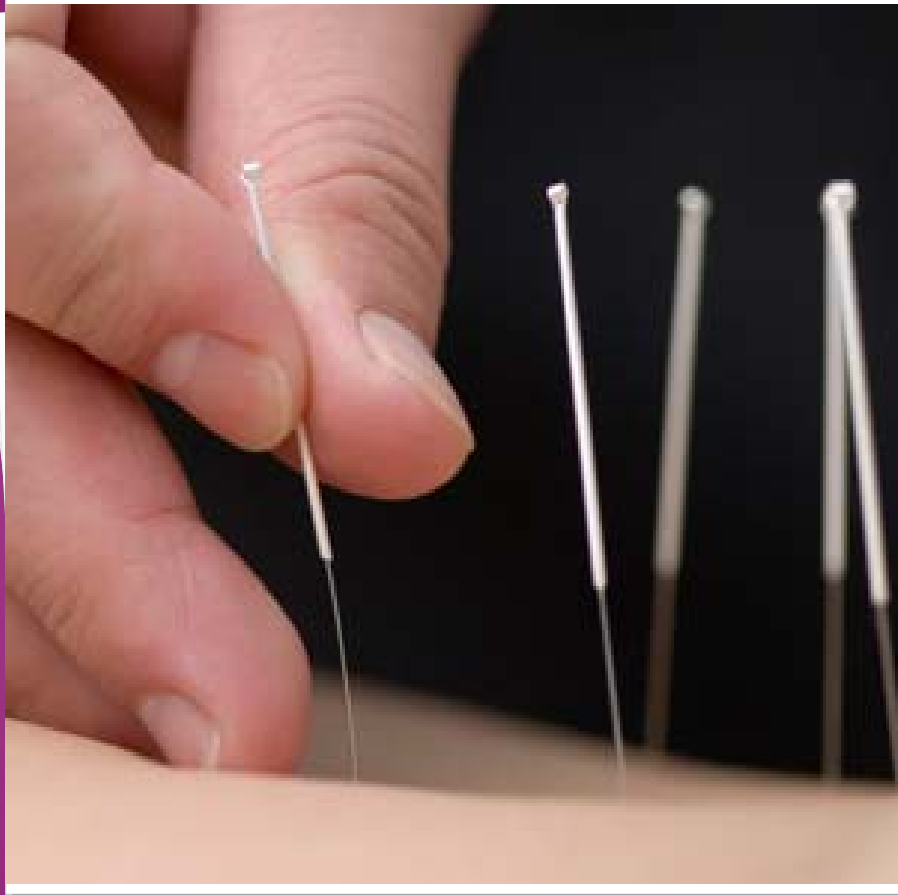
— Community Member



NAIL SALON PROJECT

- Asian Health Services and a researcher at CPIC
- Collecting information on Vietnamese American women working in nail salons in Alameda County to examine health care access and utilization and behaviors relevant to breast cancer risk.
- *Do Nail Salon workers have a higher rate of breast cancer and is it related to occupational exposures?*

FOCUS ON END-OF-LIFE



- Charlotte Maxwell
Complementary Clinic and
a researcher at UCSF
- Creating end-of-life
“ethical wills” for
underserved women with
terminal breast cancer,
their providers, and
informal caregivers.
- *Does the intervention
ease end-of-life concerns
regarding death?*

QUESTIONS?

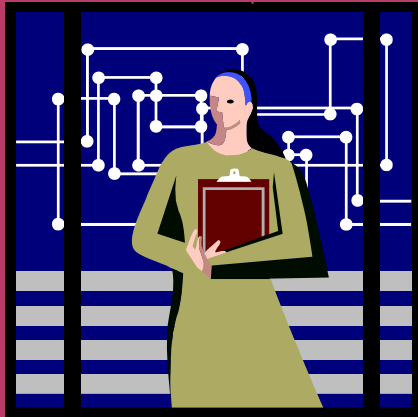
COMMUNITY AND RESEARCH PARTNERSHIPS

Marj Plumb, DrPH
Plumblin Coaching and Consulting

WORKING TOGETHER TO ANSWER COMMUNITY QUESTION



CO-PI



CO-PI



Academically Trained
Research Scientist CO-PI



Community Members & CO-PI

CO-PRINCIPAL INVESTIGATORS

- Community PI
 - Experience with the topic being researched
 - Trust of the community involved in the research
 - Skills for representing the community of interest and being a conduit with larger community
 - Sees self as a collaborator, enjoys teaching
- Academic PI
 - Trained and experienced in both the topic being researched and the research skills necessary to complete the project
 - Connected to other scientific expertise
 - Sees self as a collaborator, enjoys teaching

WHO IS THE COMMUNITY CO-PI IN THIS PHOTO?



WHAT PARTNERS BRING

Communities bring:

- Closer connection to lived experience of community
- Experience with strong intersectoral partnerships
- Innovative applied research ideas
- Understanding of cultural contexts
- Access to some funding
- Ability to affect grassroots change

Researchers bring:

- Broad experience with research in field
- Access to some funding
- Methodological expertise
- Research infrastructure, including personnel
- Theoretical frameworks
- Access to credibility
- Ethics review process
- Ability to affect policy change



ROLES OF RESEARCHER

◉ The Initiator

- Researcher generates questions, seeks out community for participation in study
 - Must be skilled in community organizing and group dynamics

◉ The Consultant

- Asked 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

WHO CAN BE THE COMMUNITY PARTNER?

- ◉ Any group of individuals sharing a given interest (cultural, social, political, health, geographic, or economic issues)
 - Can be formally organized, such as a community organization
 - Can be informally organized, such as a support group or emerging organization

ROLES OF COMMUNITY

- ◉ Co-principal investigators
- ◉ Research or project team members
- ◉ Research, project and outreach workers (interviewers, data entry, outreach)
- ◉ Community Advisory Board or Oversight Committee members (active and empowered)
- ◉ Community organization ownership, data and fiscal management

THINKING ABOUT PARTNERSHIPS

Brainstorm:

When you think of your experiences in partnerships:

- What makes them so valuable?
- What makes them so frustrating?



ARE THE PARTNERS READY TO COLLABORATE?

- ◉ There is a history of collaboration or cooperation
- ◉ Community collaborators are seen as legitimate leaders in the community
- ◉ Collaborative organizations are healthy, well-functioning, stable
- ◉ Researcher is has the training and skills required to help the team conducted quality research
- ◉ Collaborative members are self-reflective and good communicators
- ◉ Favorable political and social climate

IT'S NOT EASY TO COLLABORATE...

Community/Researcher Similarities

- ◉ Both are people who care
- ◉ They each bring unique skills and experience
- ◉ They work in complicated and stressful environments
- ◉ They have productivity goals or requirements
- ◉ They are often similarly over-worked and under-resourced

Community/Researcher Differences

- ◉ They have very specific jargon and terminology
- ◉ They have different accountability structures and 'bottom lines'
- ◉ They have different timelines and calendars
- ◉ They are not usually used to working with each other on a daily basis

PARTNERSHIP AGREEMENTS

Brainstorm:

What kind of agreements would you want to make with a researcher or community partner?



QUESTIONS?