Community-Based Participatory Research

Scientific Rigor + Community Participation = Better Research + Better Health

Sarena D. Seifer
Community-Campus Partnerships for Health
Urban Health Grand Rounds
New York, NY ~ October 21, 2005
Outline

Community-Campus Partnerships for Health (CCPH)
Community-based participatory research (CBPR):
  What is it?
  Why do it?
  What do we know about it?
  What are its prospects for the future?
  What are the continuing challenges?
  What resources are available?
Mission

To promote health through partnerships between communities and higher educational institutions
At-A-Glance

- Nonprofit organization launched in January ‘97
- Headquartered in Seattle, WA USA
- 16-member board of directors
- 1000+ members from communities and campuses across the US and a dozen countries
- Private and public funding
- Staff, students and senior consultants
Board Members

Chris Atchison, University of Iowa School of Public Health
Renee Bayer, University of Michigan School of Public Health
Cynthia Barnes-Boyd, Neighborhoods Initiative, University of Illinois-Chicago Great Cities Institute
Chuck Conner, West Virginia Rural Health Education Partnership, Spencer, WV
Diane Downing, Arlington County Dept. of Human Services, VA
Elmer Freeman, Center for Community Health Education, Research and Service, Boston, MA
Barbara Gottlieb, Brookside Community Health Center, Jamaica Plain, MA
Board Members

Larry Green, Comprehensive Cancer Center, San Francisco, CA
Ella Greene-Moton, Flint Odyssey House, Inc. Health Awareness Center, MI
Susan Gust, Partners Three Consulting, Minneapolis, MN
Dennis Magill, Wellesley Central Health Corporation, Toronto, Canada
Daniel E. Korin, Lutheran Medical Center, NY
Carmen Patrick, Emory University medical student, Atlanta, GA
Richard W. Redman, University of Michigan School of Nursing
Monte Roulier, Community Initiatives, Columbia, MO
Douglas Simmons, University of Texas, Houston Health Science Center Dental Branch
What we mean by “community” is dynamic and inclusive; there is no “one” definition of community.

Community need not be defined solely by geography. It can refer to a group that self-identifies by age, ethnicity, gender, sexual orientation, disability, illness or health condition.

It can refer to a common interest or cause, a sense of identification or shared emotional connection, shared values or norms, mutual influence, common interest, or commitment to meeting a shared need.

Institutions and individuals based out of institutions can be “the community” in certain situations. Grassroots organizations and community residents can be “the community” in certain situations.
Defining “community” in a community-campus partnership is more about the process of asking questions than about a strict definition of who “is” community or “represents” community:

“Are those most affected by the problem at the table? Are community members at the table? Are those who have a stake in the issue being addressed at the table? Do they play decision making roles?”

The purpose of the partnership drives the definition, therefore each effort must ask for the definition of community.
CCPH Principles of Partnership

- Partners have agreed upon mission, values, goals and measurable outcomes for the partnership.
- The relationship between partners is characterized by mutual trust, respect, genuineness, and commitment.
- The partnership builds upon identified strengths and assets, and addresses needs.
- Power is balanced among partners and resources are shared.
CCPH Principles of Partnership

- There is clear, open and accessible communication between partners
- Roles, norms and processes for the partnership are established with the input and agreement of all partners
- There is feedback to, among and from all stakeholders in the partnerships
- Partners share the credit for accomplishments
- Partnerships take time to develop and evolve
Major Strategies

- Create and expand opportunities for collaboration and information sharing
- Promote awareness about the benefits of community-campus partnerships
- Advocate for policies that facilitate and support community-campus partnerships
- Support service-learning and community-based participatory research in higher education
Related Projects

**National Study of the Community Involvement of Academic Health Centers**

*Funded by The Pew Charitable Trusts and Corporation for National Service*


**Community-University Partnerships for Health Research: Infrastructure Requirements**

*Funded by National Institutes of Health*

Related Projects

Examining Community-Institutional Partnerships for Prevention Research Project

Funded by the Centers of Disease Control and Prevention through a cooperative agreement with the Association of Schools of Public Health


Commission on Community-Engaged Scholarship in the Health Professions

Funded by the WK Kellogg Foundation


Community-Engaged Scholarship Toolkit

www.communityengagedscholarship.info

Multiple funding agencies – see website for details
What is CBPR?

“...a partnership approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process; with all partners contributing their expertise and sharing responsibility and ownership to enhance understanding of a given phenomenon, and to integrate the knowledge gained with interventions to improve the health and well being of community members.”

Israel, BA Annual Review of Public Health, 1998
What is CBPR?

“A collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings”.

W.K. Kellogg Foundation, 2001

“Scientific inquiry conducted in communities in which community members, persons affected by condition or issue under study and other key stakeholders in the community’s health have the opportunity to be full participants in each phase of the work – conception, design, conduct, analysis, interpretation, conclusions and communication of results.”

Federal Interagency Working Group on CBPR, 2003
Respect each other’s contributions;
Encourage change & promote knowledge to benefit community;
Share credit and responsibility for results;
Promote an emphasis on locally relevant health issues;
Examine social, economic and cultural influences on health;
Collaborate on all major phases of the research process;
Treat research participants ethically;
Furnish results to the community in a useful manner;
Utilize community strengths and expertise; and
Link research to action to enhance community capacity.
Community-Based Participatory Research (from AHRQ evidence report on CBPR)

C. helps identify key issues
\[\rightarrow \text{Incr. motivation to participate}\]
C. helps with study design, budget, proposal submission
\[\rightarrow \text{Incr. acceptability and “buy-in”}\]
C. gives guidance re recruitment and retention
\[\rightarrow \text{Enhanced recruitment and retention}\]
C. helps with measures development and testing
\[\rightarrow \text{Increased reliability and validity}\]
C. helps guide intervention development
\[\rightarrow \text{Greater relevance and likelihood for success}\]
C. helps with data interpretation and publications
\[\rightarrow \text{Enhanced potential for translation and dissemination}\]

Health Concerns Identified

Study Designed and Funding Sought

Participants recruited and retention systems implemented

Measurement instruments designed and data collected

Intervention designed and implemented

Data analyzed and interpreted
Translation of findings

Issues selected from Epid. data

Design: science and feasibility
Budget: research expenses

Recruitment and Retention based on science and “best guesses”

Measures adopted or adapted from other studies, psychometric testing

Intervention designed by researchers based on literature and theory

Researchers report findings from analysis and publish in peer review journals
Why Do CBPR?

Overcomes separation of individual from culture and context that often occurs with categorical approaches
Joins partners with diverse skills, knowledge, expertise and sensitivities to address complex problems
Establishes trust between communities & researchers
Improves research quality & validity by engaging local knowledge and theory
Studies and addresses community-identified needs
Enhances relevance of research questions & data
Translates research into practice & policy change
Increases community capacity for research
Provides voice (e.g. power, capacity, control) to communities and their members
Improves health and well-being of communities involved To effect political and social change
Ingredients of Successful Partnerships

- Trusting relationships
- Equitable processes and procedures
- Diverse membership
- Tangible benefits to all partners
- Balance between partnership process, activities and outcomes
- Significant community involvement in scientifically sound research
- Supportive partner organization policies and reward structures
- Leadership
- Culturally competent and appropriately skilled staff and researchers
- Collaborative dissemination
- Ongoing partnership assessment, improvement and celebration
- Sustainable impact

Examining Community-Institutional Partnerships for Prevention Research Group, 2004
Ingredients of Successful Partnerships

“You can’t just walk in with the expectations of creating a partnership. It takes time to develop mutual understanding and make sure you don’t exploit.”

“There is suspicion of dominant institutions. If I go into communities, all the relationship building is personal. People need to get to know me and trust me personally and know that I will deliver and not just disappear after the study. This happens over time.”

“It is key that all partners benefit, are clear what the benefits are and resources are shared.”

“In our work together...we look at how the intervention might be sustainable and appropriate given our missions.”
AHRQ Report:
CBPR: Assessing the Evidence
July 2004
www.ahrq.gov/clinic/evrptpdfs.htm

How has CBPR been implemented to date with regard to the quality of research methodology and community involvement?
What is the evidence that CBPR efforts have yielded the intended outcomes?
## Characteristics of CBPR Studies

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number</th>
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</thead>
<tbody>
<tr>
<td>General characteristics</td>
<td></td>
</tr>
<tr>
<td>Total number of studies identified</td>
<td>60</td>
</tr>
<tr>
<td>Average number of publications per study</td>
<td>2</td>
</tr>
<tr>
<td>Publication dates of the first article from the study</td>
<td>Percent</td>
</tr>
<tr>
<td>Before 1980</td>
<td>2%</td>
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<tr>
<td>1980-1985</td>
<td>0%</td>
</tr>
<tr>
<td>1986-1990</td>
<td>3%</td>
</tr>
<tr>
<td>1991-1995</td>
<td>13%</td>
</tr>
<tr>
<td>1996-2000</td>
<td>42%</td>
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<tr>
<td>2001 to 2003</td>
<td>40%</td>
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### Characteristics of CBPR Studies

<table>
<thead>
<tr>
<th>Substantive Topics</th>
<th>Percent</th>
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<tbody>
<tr>
<td>General health concerns</td>
<td>18%</td>
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<tr>
<td>Environmental hazards</td>
<td>15%</td>
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<tr>
<td>Hypertension/heart disease/diabetes</td>
<td>13%</td>
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<tr>
<td>Services for HIV/AIDS</td>
<td>10%</td>
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<tr>
<td>Substance abuse including smoking</td>
<td>8%</td>
</tr>
<tr>
<td>Cancer screening and prevention</td>
<td>7%</td>
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<tr>
<td>Women’s health</td>
<td>7%</td>
</tr>
<tr>
<td>Asthma prevention</td>
<td>3%</td>
</tr>
<tr>
<td>Occupational health</td>
<td>3%</td>
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<tr>
<td>Seniors’ health</td>
<td>3%</td>
</tr>
<tr>
<td>Other miscellaneous concerns (disabilities, hospice access, childhood immunization, nutrition, mental health)</td>
<td>12%</td>
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Type of Study and Research Design

<table>
<thead>
<tr>
<th>Type of Study</th>
<th>Percent of Studies</th>
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<tbody>
<tr>
<td>Nonexperimental designs</td>
<td>50%</td>
</tr>
<tr>
<td>One-group pre and posttest studies</td>
<td>30%</td>
</tr>
<tr>
<td>Observational</td>
<td>15%</td>
</tr>
<tr>
<td>Quasi-experimental designs</td>
<td>5%</td>
</tr>
<tr>
<td>Experimental designs</td>
<td>0%</td>
</tr>
</tbody>
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Type of Study:
- Evaluated intervention: 10%
- Intervention either incomplete or not evaluated fully: 40%
- Non-interventional: 50%
Community Involvement

<table>
<thead>
<tr>
<th>Type of Community Involvement</th>
<th>Percent of Studies</th>
</tr>
</thead>
<tbody>
<tr>
<td>Selection of Research Question</td>
<td>75%</td>
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<tr>
<td>Proposal Development</td>
<td>50%</td>
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<tr>
<td>Financial Responsibility for Grant Funds</td>
<td>25%</td>
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<tr>
<td>Study Design</td>
<td>0%</td>
</tr>
<tr>
<td>Recruitment and Retention</td>
<td>0%</td>
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<tr>
<td>Measurement Instruments and Data Collection</td>
<td>0%</td>
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<tr>
<td>Intervention Development, Implementation</td>
<td>0%</td>
</tr>
<tr>
<td>Interpretation of Findings</td>
<td>0%</td>
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<tr>
<td>Dissemination of Findings</td>
<td>0%</td>
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<tr>
<td>Application of Findings to Health Concern Identified</td>
<td>0%</td>
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Comparing Research Quality and Community Involvement across Study Designs

Study Design

- Experimental designs
- Quasi-experimental designs
- Observational studies
- One-group pre and posttest studies
- Nonexperimental designs

Scores for research quality
Scores for community involvement

Scores (1–3)
“High quality research and intense community involvement are not contrary to each other.”
Bottom Line:

“In many areas of health promotion & disease prevention, researchers and community advocates alike are beginning to focus their efforts further “upstream” in the socio-ecologic model, encouraging a greater emphasis on policy and environmental changes that facilitate proactive health choices at the individual level. CBPR is well positioned to address such approaches…”

Kaplan 2000
The Growth & Growing Legitimacy of CBPR

- Grant funding – *including funders who “don’t fund research”*
- Community-based and academic peer reviewers
- Post-doctoral fellowships
- Job announcements
- Journal articles, theme issues, reports, new journal
- CBPR listserv
- Community-based CBPR centers
Community distrust of academic institutions
Time involved
Unequal power dynamics
Unequal distribution of grant money
Scientific rigor vs. community acceptability
Skepticism about rigor, validity and value of CBPR
Faculty review, promotion and tenure policies
Staff job descriptions and performance expectations
Lack of support from leadership
Institutional review board policies
Community advisory boards as a funder requirement and not a genuine participatory process
Resources in your own backyard


Resources in your own backyard


Resources
Through Community-Campus Partnerships for Health

Training Institutes
Customized Consultation
National Conference
Online Newsletter
Electronic Discussion Groups
Resource Guides & Toolkits
Promising Practices

www.ccph.info
Mark Your Calendars!

**APHA Conference** – CBPR institute – December 2005, Philadelphia, PA - Registration Now Open

**9th Conference** - May 31-June 3, 2006, Minneapolis, MN – Registration Now Open

**9th Service-Learning Institute** – July 21-24, 2006 in WA State – Applications available in November 2005

**5th Annual Award** – Call for nominations out in November 2005
Stay Connected

CBPR Listserv
Co-sponsored by CCPH and Wellesley Central Health Corporation
https://mailman1.u.washington.edu/mailman/listinfo/cbpr
or www.ccph.info
Community-Campus Partnerships for Health

We invite you to join a growing network of communities & campuses that are collaborating to promote health

Contact us by phone 206-543-8178 or email at ccphuw@u.washington.edu or visit us online at www.ccph.info