Promoting Health Equity & Social Justice through Community-University Partnerships

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STORIES OF ENGAGEMENT: BUILDING PARTNERSHIPS IN HEALTH RESEARCH
COMMUNITY ENGAGEMENT SYMPOSIUM
Community-Based Participatory Research is....

“...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 (that’s 14 years ago!!)
Mission

To promote health equity & social justice through partnerships between communities & academic institutions.
Partnerships form to serve a specific purpose and may take on new goals over time.

Partners have agreed upon mission, values, goals, measurable outcomes and accountability for the partnership.

The relationship between partners is characterized by mutual trust, respect, genuineness, and commitment.

The partnership builds upon identified strengths and assets, but also works to address needs and increase capacity of all partners.

The partnership balances power among partners and enables resources among partners to be shared.
Partners make clear and open communication an ongoing priority by striving to understand each other's needs and self-interests, and developing a common language.

Principles and processes for the partnership are established with the input and agreement of all partners, especially for decision-making and conflict resolution.

There is feedback among all stakeholders in the partnership, with the goal of continuously improving the partnership and its outcomes.

Partners share the benefits of the partnership's accomplishments.

Partnerships can dissolve and need to plan a process for closure.
1. Quality processes

“We are not just talking about a process that involves partners. There needs to be a process of shared decision making.”

~ Ella Greene-Moton, Flint, MI

Relationship focused…open, honest and respectful…trust-building…acknowledging of history…committed to mutual learning…sharing credit
2. Meaningful outcomes that are tangible and relevant to communities

“OK, we can work together on community-based participatory research, but only if you support our kids in the pipeline. Bring them to campus for programs, teach them skills they use to be more marketable, give them academic credit.”

~ Vickie Ybarra, Toppenish, WA

Eliminating health disparities…affordable housing…education, economic development…
3. Transformation at multiple levels

“We build social capital when we’re doing this work. We don’t often talk about that.”

~ Douglas Taylor, Atlanta, GA

- Personal transformation, including self reflection and heightened political consciousness
- Institutional transformation, including changing policies and systems
- Community transformation, including community capacity building
- Transformation of science and knowledge, including how knowledge is generated, used and valued and what constitutes “evidence”
- Political transformation, including social justice

Framework for Authentic Partnerships

Citation: Achieving the Promise of Authentic Community-Higher Education Partnerships: Community Partners Speak Out! CCPH, 2007
Achieving the Promise of Community-Engaged Health Disparities Research: A National Community Partner Forum

December 5-7, 2011 ~ Boston, MA

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Why a National Community Partner Forum?

Community engagement in research is central to understanding and addressing disparities in health. Research funding agencies are supporting faculty and institutions to engage communities as partners in conducting research. There are few supports for communities to engage faculty and institutions as partners, or to conduct our own research.

As more community organizations engage in research, it is clear that they need their own networks for professional development, mentoring and advocacy.
"Communities need to be prepared for the avalanche of health research that's coming down the pike. We need to arm ourselves with the knowledge and skills to not only engage as partners in research, but to inform what research gets funded, how it is carried out and how it is used...The health of our communities is at stake."

~ Ann-Gel Palermo, Chair, Harlem Community & Academic Partnership & Member, Forum Planning Committee
Forum Planning Committee

Willie Mae Bennett-Fripp, Executive Director, Committee for Boston Public Housing, Boston, MA
Grace Damio, Director of Research and Service Initiatives, Hispanic Health Council, Hartford, CT
Elmer Freeman, Executive Director, CCHERS, Boston, MA
Susan Gust, Community Activist, Minneapolis, MN
Loretta Jones, Founder & CEO, Healthy African American Families, Los Angeles, CA
Alma Knows His Gun McCormick, Executive Director, Messengers for Health, Hardin, MT
Ann-Gel Palermo, Chair, Harlem Community & Academic Partnership, New York, NY
Forum Planning Committee

Fernando Pineda-Reyes, Executive Director, Community, Research, Education & Awareness (CREA) Results, Denver, CO

Alex Pirie, Coordinator, Immigrant Service Providers Group/Health, c/o Somerville Community Corporation, Somerville, MA

Jean Schensul, Senior Scientist & Founding Director, Institute for Community Research, Hartford, CT

Peggy Shepard, Executive Director, WE-ACT for Environmental Justice, New York, NY

Eric Wat, Director, Research and Evaluation Unit, Special Service for Groups, Los Angeles, CA
Karen Calhoun, City Connect, Detroit
Amal Killawi, Detroit
Angela Reyes, Detroit Hispanic Development Corporation
Zachary Rowe, Friends Of Parkside & Detroit URC
Ella Greene-Moton Flint Community Based Organization Partner, CBPH Caucus & National Community Based Organization Networ, Flint, MI
Lisa Oliver-King, Our Kitchen Table, Grand Rapids, MI
Forum Participants

Location: 27 states and DC
Setting: 80% urban, 11% rural, 3% frontier, 6% Native Nation
Race/ethnicity*: 47% African-American, 23% Caucasian, 20% Hispanic, 10% Mixed, 8% Asian, 4% Pacific Islander, 3% American Indian/Alaska Native
Gender: 60% women, 40% men
Research experience: 57% involved in community-engaged health disparities research for over 5 years, 24% for 3-5 years, 16% for 1-3 years, 3% for less than one year
Research roles*: 70% research team member, 36% principal investigator (PI), 50% co-PI, 67% community advisory committee member, 9% Institutional Review Board member

*multiple choices could be selected
Over 80% of participants are involved in federally funded community-engaged research, including*:
30% NIH Clinical and Translational Science Awards (CTSA)
23% CDC Prevention Research Centers
20% National Institute of Minority Health and Health Disparities
17% NIH Partners in Research Program
15% National Cancer Institute
8% National Institute of Environmental Health Sciences
8% Native American Research Centers for Health
5% Environmental Protection Agency

*multiple choices could be selected
Forum Guiding Questions

1. How do we ensure that communities most affected by health disparities have a voice at the tables that decide what research gets conducted, how and by whom?

2. How do we support communities most affected by health disparities to conduct and manage their own research?

3. How do we ensure that communities work as equal partners with universities and other institutions to make sure that community research interests are met?

4. How do we ensure that social justice is central to community-engaged research?

5. How do we form effective networks for furthering dialogue and action around community knowledge development and equitable community-academic partnerships?
Premises Reinforced
at the Forum

1. CBPR could simply replace the conventional research methodology without embracing social change, policy change, paradigm shifts and power sharing.

2. Community partners must have the knowledge and the supportive network to be able to challenge the status quo, avoid the pitfalls and maximize the benefits of research.

3. Community partners need to be adequately supported for their roles in research.

4. Community partners need to be at the decision making tables that shape research and be able to rapidly respond to opportunities to influence research policy.
Re-Define Cultural Norms & Terms and Coin New Ones

"""We need to acknowledge and honor multiple ways of knowing"

We are community activist researchers, many of us have sidewalk PhDs
What is science? What is evidence? What is research? What is CBPR? Who is a “peer” (as in peer review)? Who gets to define these terms?
Dissemination isn’t the end-point of research & it’s more than journal articles
Randomized clinical trials focus on individual change – community level research is about systems change
Develop Research-Ready Communities

“As more established CBOs, we have a responsibility to mentor & train newer CBOs”

Assess readiness
Understand & navigate research processes and systems
Decide whether & how to obtain a federally negotiated indirect rate, establish a research review board
Know it’s ok to say no & when to say no
Questions to ask of prospective partners
What to include in a Memorandum of Understanding (MOU)
What community engagement in research can look like
Establish policies for data ownership, review, dissemination
Compensate Communities for Research & Teaching Roles

“Our expertise is not free”

Identify & articulate our assets and skills
Cost out the time & money it takes to do CBPR
Negotiate benefit package: $, certification, continuing education units, free classes
Negotiate direct & indirect costs – share examples
Work with university fiscal offices to pay CBOs up-front, not by reimbursement
Exchange Existing & Develop New Resources

“There’s no reason to reinvent the wheel”

Negotiating indirect costs coming back to partnership
MOUs & guidelines on what to include/how to negotiate
University-CBO subcontracts (and vice versa)
Authorship & data ownership agreements
Funded proposals
Creative dissemination of research results
CBO roles, rights and responsibilities
CBO research training programs & pilot grant funding
Cultivate Funders

“Social justice funders who ‘don’t fund research’ may invest in CBPR”

Have dialogue with CBPR Funders Interest Group
Develop list of “friendly” funders & program officers
“Make the case” for funding for relationship building and research infrastructure in communities (e.g., personnel, training, data systems, ethics review)
Develop Community-Ready Researchers & Institutions

“We have a critical role to play in developing the capacity of our academic partners”

CBO mentoring of researchers and students
Appoint community faculty
Require ethics training for researchers on engaging with community
Hold Funders, Institutions & Researchers Accountable

“There’s a lot of rhetoric about CBPR – but is it really happening on the ground?”

Release a CBPR report card: Highlight leaders & support those needing improvement
Create an ombudsman position, offer legal aid
Audit/monitor federal funding for research
Move from advisory boards to decision-making boards
Publish articles & share stories – both good and bad
Provide open access to papers when they’re published
Support for community partners to attend & present at conferences
Change Research Ethics
Review Policies & Practices

“Ethical research is more than protecting individual study participants”

Include language in the federal regulations regarding exploitation of communities, community risks & benefits
Recruit more community members to serve on IRBs
Train IRB members in how to review CBPR
Develop and support community IRBs
Cultivate & Position Leaders

“We need to position leaders for high impact positions & support them through the process”

Federal advisory councils
Office of Human Research Protections
Grant review panels
Institutional Review Boards
Community boards
Strategic university committees
Change NIH Policies & Practices

“It’s a no-brainer: funds for community research infrastructure should come to communities”

Draft model funding announcement for community research infrastructure
Draft model funding announcement for CBPR
Submit list of community-based peer reviewers
Develop profiles of CBOs with track records in research funding & impact – it can be done!
Peer certification of CBOs who are “ready” to be directly funded
We Want *Health Research* Equity
Immediate Outcomes & Next Steps

“We need to build on the momentum we’ve created here”

Post forum presentations & notes online
Disseminate report & publish journal articles
Support workgroups
  Training & Mentoring
  Leadership Development
  Redefining Norms
  Community Centers of Excellence
  Policy & Advocacy
Immediate Outcomes & Next Steps

“We need to build on the momentum we’ve created here”

Jan 18 – CBPR Funders Interest Group via phone
Mar 6 – Congressional health staff briefing in DC
Mar 7 – Community IRBs & review boards in NYC
Mar 8 – NYC community partner forum
Mar 20 – House Appropriations Hearing on NIH Budget
Apr 6 – Submitted comments on future of CTSA
Apr 18 – Presentations at CCPH conference in Houston
Apr 24 – Presentations at Congressional Black Caucus
Federal Policy Recommendations

Fund authentic community-based participatory research
Fund community-based organizations (CBOs) for research capacity-building & infrastructure
Require authentic community engagement in Clinical & Translational Science Awards (CTSAs)
Establish ombudsman for community-academic disputes
Conduct audits of federal research funding

Applicants, grantees/sub-grantees & reviewers: # and % of CBOs

NIH funding: $ for CBPR and health disparities research; $ to CBOs

Indirect rates: rates used for CBPR, % applied to the funded research project, % applied to communities/CBOs
DEVELOPING AND SUSTAINING COMMUNITY-BASED PARTICIPATORY RESEARCH PARTNERSHIPS: A SKILL-BUILDING CURRICULUM

Resources for Community-Based Participatory Research
www.ccpph.info

CBPR RESOURCES WEBSITE
Resources on the site include:
- Principles, policies, reports, presentations and curricula
- Opportunities for funding, training and technical assistance
- Links to related organizations and initiatives

Visit the website today at http://obots.washington.edu/cbpr/curriculum

DEVELOPING & SUSTAINING CBPR PARTNERSHIPS:
A SKILL-BUILDING CURRICULUM
This evidence-based curriculum is intended as a tool for partnerships that are planning to use a CBPR approach to improving health. Each of 7 units includes:
- Learning objectives
- Short, in-depth content information about the topic(s) being presented
- Examples & interactive exercises
- Elaborate & suggested resources

Visit the curriculum today at http://www.ccpphcurriculum.info

INSTITUTIONAL REVIEW BOARDS & CBPR
The Expert call series covered such topics as "Supplementing CBPR with a Community Advisory Board," and "Creating an Independent Community Site: What's Right for You?"

Download audio files & handouts at http://obots.washington.edu/cbpr/audios.html
Sign up for the CBPR & Research Ethics Electronic Discussion Group at http://listserv.ohsu.edu/software/lists��/subscribe.html

CBPR RESOURCES BY & FOR COMMUNITY PARTNERS
The Community Partners Peer Mentoring & Advocacy Website is designed as a resource for community members and community groups in their work with academic partners.

Visit the website today at http://obots.washington.edu/cbpr/cpp.html

CBPR ELECTRONIC DISCUSSION GROUP
Site on top of the other CBPR news and funding opportunities! Co-sponsored by CPHA and the Wednesday Institute, the forum has over 1,300 subscribers, including community organizations, colleges & universities, funding agencies, and policy makers.

Sign up at http://listserv.ohsu.edu/software/lists��/subscribe.html

CBPH CONSULTANCY NETWORK
Looking for a CBPR expert to give a presentation, lead a workshop, conduct an evaluation, or provide technical or on-site consultation? The CBPH Consultancy Network is here to help!
Learn more at http://obots.washington.edu/cbpr/consult.html

Community-Campus Partnerships for Health promotes health (broadly defined) through partnerships between communities and higher educational institutions. Become a member today at www.ccph.info.
Community-Engaged Scholarship Toolkit

Community-Engaged Scholarship for Health

CES4Health.info is a free online mechanism for peer-reviewing, publishing and disseminating products of health-related community-engaged scholarship that are in forms other than journal articles. For example, videos, manuals, curricula and products developed through service-learning, community-based participatory research and other community-engaged work.

Through CES4Health.info, you can:
- Search for high quality tools and resources
- Submit products for peer review
- Apply to be a peer reviewer
- Contribute to the field of community-engaged scholarship... and ultimately the health of communities!

NEW PRODUCTS
- Guide to Enhancing Grassroots Risk Communication: Annu
- Improving the Health of Conditions, Mental Health, Social Capital and Communities Facing Lower Income
- Community-Engaged Approaches to Multilevel Partnerships

HOT TOPICS
- Join Community-Campus Partnerships for Health Today!
- Stay on Top of CRM Funding Opportunities
- Attend the CEPH Conference, May 12-15, in Portland, OR
- Faculty: Make Your Best Case for Prevention & Treatment!
For More Information

Email me at sarena.seifer@gmail.com
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