The Promise and Pitfalls of Community-Based Participatory Research: Lessons Learned by Researchers, Community Partners and Funders

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GOAL: To draft a report for NIH’s Office of Behavioral and Social Sciences Research on the infrastructure required to develop and sustain community-based participatory research (CBPR) partnerships

- To inform the development of possible NIH-sponsored initiatives
- To contribute to our knowledge about CBPR
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A collaborative approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process. The partners contribute unique strengths and shared responsibilities to enhance understanding of a given phenomenon and the social and cultural dynamic of the community, and integrate the knowledge gained with action to improve the health and well-being of community members. (Israel, 1998)
Benefits of CBPR

- Bridge individual, culture and context
- Establish trust between communities & researchers
- Improve research quality & validity by engaging local knowledge and theory
- Enhance relevance of research questions & data
- Translate research into practice & policy change
- Study and address community-identified needs
- Increase community capacity for research
Infrastructure

- The sum of those elements that are essential and/or required to support activity leading to successful research processes and outcomes.

- Broad themes included: community-university relationship, policies and procedures, financial resources, human resources, “hard” infrastructure.
Methods

- Literature review
  - review articles
  - empirical articles that draw from 2+ CBPR projects
  - conference proceedings

- Structured telephone interviews
  - web-based search for research centers that conduct CBPR
  - snowball sampling
  - 30 interviews conducted: 9 principal investigators, 9 program managers, 6 community partners, 6 funding agency program officers; 18 women; All regions of U.S.
Defining and Developing Successful Partnerships

- Partnership must be in place
  - universities often not viewed as partner
  - history of poor relationships between community & campus
  - community partners serve as "gatekeepers"
  - build relationships and trust over time
  - cultural competency

- Guidelines & principles
  - process is nearly as important as the actual principles

- Balance between process and activities/action

- Ongoing assessment and improvement
CBPR principles (Israel et. al.1998)

- recognizes community as a unit of identity
- builds on strengths and resources within the community
- facilitates collaborative, equitable involvement of all partners in all phases of the research
- integrates knowledge and intervention for mutual benefit
- promotes co-learning and empowering process that attends to social inequalities
- involves cyclical and iterative process
- addresses health from multiple perspectives
- disseminates finding and knowledge gained by all partners
- involves long-term commitment by all partners
Defining and Developing Successful Partnerships

"Approaching the partnership with the belief that community participation is an expectation not a chore."

"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."

"It is key that both partners benefit, are clear what the benefits are and resources are shared."
“Researchers get a bad reputation as communities can feel heavily researchers - people can feel like they were involved but did not benefit. There is a problem with the dissemination of findings.”

“Growing up in a racist country can cause 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.”
Institutional Culture, Policies and Procedures

Facilitating factors at the institutional level:

- prior relationships
- alignment of vision & mission with CBPR principles
- authentic participatory, partnership process
- institutional structures for community-university partnerships
- strong leadership at all levels, with explicit actions
- value faculty & student involvement in the community, staff & volunteer involvement with the campus
- value interdisciplinary collaboration
- promotion of the partnerships in a non-exploitive manner
Institutional Culture, Policies and Procedures

- Challenges and barriers at the institutional level:
  - 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
  - value placed on grants that fully pay for indirect costs
  - institutional review board policies
Institutional Culture, Policies and Procedures

- Policies that strengthen CBPR partnerships:
  - Memos of understanding, partnership agreements
  - Community advisory board endorsements and veto powers
  - Mission, by-laws, decision-making processes, membership
  - Hiring, authorship, dissemination
  - Budget and fiscal policies
  - Process and impact evaluation
  - Faculty review, promotion and tenure
  - Community agency staff job expectations
  - Human subjects policies
  - Communication policies
“The university does not do anything to undercut the partnership’s work. But, it does not do much to facilitate it. The university generally does helpful things if they are cost-neutral.”

“Leadership is important - people at the top saying it’s important - for example, at the level of the Dean.”

“My board allows us to attend meetings and participate in programs supporting the partnership”. 
“It is important that not all of the grants be funneled directly through the University as this may convey a message of dominance.”
Community involvement and infrastructure

Facilitators:
- Non-hierarchical structures
- Community advisory structures
- Community members in positions of power
- Jointly developed norms, principles and signed agreements
- Project manager/liaison position
- Technical assistance
- Financial support
Community involvement and infrastructure

Challenges and concerns:

- Community advisory boards as a funder requirement and not a genuine participatory process
- Imbalance of power and control over resources
- Cultural conflicts
- Conflicts of priorities
- Funding pressures
Community involvement and infrastructure

Community roles

- Agency representatives, residents
- Volunteers, central staff, field staff
- Advisors, decision makers, co-investigators
“In our work together we try to ascertain what kinds of resources would be available...we look at how the intervention might be sustainable and appropriate given the agency’s mission.”

“Having an executive board chaired by the community majority has more teeth than just acting in an advisory capacity.”
“Must of the research has not been culturally sensitive. The Center is in the heart of a city that has largely residents of color but the Center is mostly white. There has been insensitivity to cultural issues and no dissemination of research results. The community advisory committee has had to deal with all of this. Now the community requires that researchers describe their dissemination plans [as part of the research proposal].”
CBPR requires significant human resources:
- Project manager based largely in the community
- Partners should be involved in hiring key staff
- Priority on hiring community residents
- Require unique knowledge, skills and attitudes
- Ongoing training and professional development
- Researchers should be visible in the community
Staffing configurations varied, but several positions considered essential:

- Individuals in positions of authority in the university and in community agencies, balanced leadership
- Individuals who manage the partnership process
- Data management position based in the community agency
- Multidisciplinary principal investigators
- Staff hired from the community
- Administrative and clerical staff, fiscal staff, project-specific staff, students
Human resources

Community-Campus Partnerships for Health

- Staff knowledge, skills and competencies
  - Interpersonal and facilitation skills
  - Technical skills
  - Connections to the community
  - Commitment to the substantive issue and the partnership process
Community-Academic Liaison: Ideal Job Description

- Shared position or two positions - in campus, in community
- Establish trust among partners, build relationships
- Act as a point person for problem-solving
- Support community advisory board
- Develop policies and procedures
- Supervise students or research assistants
- Assist with research
- Bring in new community partners
- Support new academic partners
- Balance demands among partners
Community-Academic Liaison: Ideal Job Description

- Direct personal knowledge of the community
- Positive track record of working in communities
- Interpersonal and facilitation skills
- Technical skills
- Cultural competency skills
- Commitment to the substantive issues and the partnership process
“Come out of the office and meet with the community to see what’s going on in terms of the value of the research to the community. Sometimes things are judged from afar, but you need to have first-hand knowledge and be willing to communicate.”
Many funding agencies do not understand CBPR...
- timelines do not account for time to develop relationships
- grant reviewers do not understand CBPR
- categorical grants hinder creative problem-solving and interdisciplinary collaboration
- categorical grants define the problem rather than allowing communities to define the problem
- limited opportunities for community-based organizations to be research grant recipients
- grants build infrastructure within universities but not within communities
...But this is changing

- Private foundations seen as more responsive to CBPR
- Increased NIH emphasis on social and behavioral sciences
- CDC, NIEHS, NCI, HUD, AHRQ, Kellogg CHSP
- Some funding agency program officers believe their RFPs support CBPR but they’re receiving few CBPR proposals
- Federal interagency working group on CBPR

Other concerns:

- Centers vs. individual investigators
“The key to funding community-university research partnerships is getting NIH on board”

“How do we deal with the reviewer problem at NIH? Reviewers don’t understand CPBR methods and don’t understand diverse communities.”

“If the funders speak, they will come. If this type of research is clearly a priority of big funders then the university will offer more support.”
“Given the long history of community-placed research, with little or no community participation...the SPNs are strongly encouraged to take the time and invest the resources needed to ensure full community participation and/or support of all SPN sponsored research.”

Special Populations Networks for Cancer Awareness Research and Training
National Cancer Institute, 2002
CBPR is often viewed by the academic community at best as inferior to other forms of research and at worst as not even research. This perception contributes to challenges with gaining academic support in such areas as promotion and tenure.

- Assess and expand evidence base for CBPR
- Increase # of peer-reviewed journals that publish CBPR
- Restructure faculty promotion and tenure policies to recognize and reward community-based scholarship
- Increase federal funding for CBPR
- Prepare IRBs for proposals that include CBPR
The process of developing and sustaining partnerships is not often valued and recognized by the funding and academic communities as an essential part of the methodology of CBPR. This process takes time and is significantly strengthened by having a permanent staff person who serves as a community-academic liaison for the partnership.

- Provide support for planning, relationship-building and partnership development as an essential part of the methodology of CBPR
Funding mechanisms, policies and procedures are often biased against CBPR. This bias can be implicit or explicit and may be inadvertent, but is a concern nevertheless.

- Facilitate opportunities for funding agencies to expand their knowledge of CBPR & exchange information with the field.
- Allow funding to be used for expenses associated with meeting space, food, hard infrastructure, administration, program evaluation.
- Design funding initiatives to encourage or require CBPR.
- Recruit and prepare reviewers to competently review CBPR proposals.
Limited numbers and types of academic institutions are pursuing CBPR partnerships.

- Continue and expand funding available for Centers.
- Offer technical assistance and planning grants to develop the capability of a broader range of applicants.
- Designate Centers of Excellence to serve as mentors.
- Have more open and well-publicized pre-planning meetings around forthcoming RFPs, including opportunities to comment on drafts and nominate reviewers.
Key Issues and Recommendations

More barriers than incentives exist for CBOs to engage in CBPR. The imbalance of control of power and resources between communities & campuses can undermine sustainability & significance of CBPR.

- Increase likelihood that research funds awarded to universities will pay for CBO-incurred research expenses.
- Facilitate ability of CBOs to be lead applicant & fiscal agent.
- Develop funding initiatives that address community-identified research priorities.
- Require evidence of genuine community partnerships in grant proposals.
- Directly address the legacy of Tuskegee.
Conducting CBPR requires a team with a unique set of knowledge, attitudes, values and competencies that need to be cultivated and supported.

- Invest in the preparation of researchers who have the knowledge, attitudes, values and competencies to successfully conduct CBPR.
- Invest in ongoing training and professional development for all partners.
Key Issues and Recommendations

Although pursuing applied research by their very nature, CBPR partnerships do not consistently disseminate their findings for practical application.

- Offer mentor-mentee grants to mentor communities to adopt successful interventions
- Convene “research to practice” conferences
- Provide dissemination grants
- Engage national organizations of community-based organizations in the process of disseminating research findings.
There is no coordinated education and advocacy effort on behalf of CBPR, nor is there a readily accessible “one stop” source of information about CBPR.

- Convene a national conference on CBPR with an explicit action agenda.
- Establish an online resource center on CBPR.
There are important unanswered questions:

- The importance, nature and role of the community-academic liaison function.
- Time and process needed for building relationships and trust.
- Perspectives of researchers, community-based individuals and funding agencies who are not actively involved in CBPR.
- How promotion and tenure process can inhibit or facilitate CBPR.
- How the processes and policies of funding agencies can inhibit or facilitate CBPR.
- Impact of implementing recommendations made in this paper.
Limitations

- Limited literature review
- Interviews were a convenience sample
- Interview time limitations