

Issues in NIH Research Proposals on Community Based Participatory Research

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Integrated HIV Research Programs on the Mental Health of AIDS

Basic & Clinical NeuroAIDS

Neuropathogenesis
Viral/Host Genetics
Neuropsychiatry
Therapeutics

HIV Primary Prevention

Social Epidemiology
Primary Prevention

**Center for Mental Health
Research on AIDS**

HIV Secondary Prevention & Translation

Secondary Prevention
Adherence
Commun Implement
Translational

Cross-Cutting HIV Programs

AIDS Centers
Infants, Children, Adolesc
International
Training
Health Disparities
Technology Transfer

- **Epidemiology**
- **Genetics**
- **Infectious Diseases**
- **Neuroimmunology**
- **Neurology**
- **Neuropathology**
- **Neuroscience**
- **Nursing**
- **Psychiatry**
- **Psychology**
- **Public Health**
- **Radiology**
- **Social Work**
- **Sociology**

Participatory Research as an Approach

CBPR is an orientation or an attitude to research that focuses on relationships between research partners and goals of societal transformation, rather than a specific set of research methods or techniques.

(Cornwall & Jewkes, Soc Sci Med, 1995, 41:1667-1676)

Why Conduct Community-Based Participatory Research?

As an alternative to traditional health-related research to improve the lives of people in communities studied, through the implementation of three inter-related elements:

1. Participation
2. Research
3. Action

CPBR Proposes Principles Based on Assumptions that

- Genuine partnership means colearning (academic and community partners learning from each other);
- Research efforts include capacity building (in addition to conducting research, there is a commitment to training community members in research);
- Findings and knowledge should benefit all partners;
- CBPR involves long-term commitments to effectively reduce disparities

From Wallerstein, NB and Duran, B (Health Promotion Practice, July 1996, Vol. 7, no. 3, 312-323).

Contributions of Community Partnered Approach (1)

- More effectively focus research questions on health issues of greatest relevance to communities at highest risk
- Enhance recruitment and retention efforts by increasing community buy-in and trust
- Enhance reliability and validity of measurement instruments (particularly survey) through in-depth and honest feedback during pre-testing
- Improve data collection through increased response rates and decreased social desirability response patterns
- Increase accurate and culturally sensitive interpretation of findings

Contributions of Community Partnered Approach (2)

- Target interventions to the identified needs of community members
- Develop intervention strategies that incorporate community norms and values into scientifically valid approaches
- Facilitate more effective dissemination of research findings to impact public health and policy
- Increase potential for translation of evidence-based research into sustainable community change that can be disseminated more broadly

Increasing Interest In/Support for CBPR

- Institute of Medicine Report, “Who will Keep the Public Healthy? Educating Public Health Professionals for the 21st Century”
- Special Issues/sections of Journals (e.g., American Journal of Public Health, Environmental Health Perspectives, Journal of General Internal Medicine)
- National Institutes of Health Interagency Workgroup on CBPR
- Funding Opportunities through Foundations (e.g., Robert Wood Johnson—fledgling support for community-driven research projects, W.K. Kellogg—Community Health Scholars Program to train postdocs in CBPR)
- Funding Opportunities through NIH (next slide)

NIH FOAs on CBPR (1)

- NCMHD (R24): Three Phases of Community-Based Participatory Research (CBPR) Initiative in Reducing and Eliminating Health Disparities. Planning Phase (RFA-MD-05-002), Intervention Phase (RFA-MD-07-003), Dissemination Phase (not yet released)
- NCMHD (P60): Excellence In Partnerships for Community Outreach, Research on Health Disparities and Training (Project Export) (RFA-MD-06-002)
- NICHD (U13) : RFA Announcement of a Limited Competition for the Academic-Community Partnership Series (RFA HD-06-019)

NIH FOAs on CBPR (2)

- NIEHS: Ongoing PAs for “community-driven research”
- OBSSR: Community Participation in Research (interventions) (RO1: PA-08-074)
- OBSSR: Community Participation Research Targeting the Medically Underserved (RO1: PAR-08-075; R21: PAR-08-076)
- NIMH: Two Phases of Community-Based Participatory Research at NIMH (R21: PAR-07-004; RO1: PAR-07-133)

Funded AIDS Grants in Response to CBPR FOAs

- Zuninga de Nuncio ML, University of California San Diego, R21: Barriers to Care & Treatment Practices in HIV+ Latinos in US-Mexico Border Region
- Rhodes SD, Wake Forest University, R21: CBPR and the Internet: Increasing HIV Testing Through Chat Room-Based Promotion
- Behforouz H, Brigham and Women's Hospital, R21: CBPR to Develop an HIV Promotion Intervention

4 Pending Review, 13 Not Funded

Funded non-AIDS Grants in Response to CBPR FOAs

- Hassouneh DM, Oregon Health & Science University, RO1: Women Physical Disability and Depression: Communities Responding Now!
- Neal-Barnett AM, Kent State University at Kent, R21: Sister Circles for Professional African American Women with Panic Attacks

6 Pending Review, 21 Not Funded

Common Pitfalls in CBPR Proposals (1)

CBPR Specific Problems:

- Failure to demonstrate how CBPR principles are integrated in the project—how community was involved in shaping direction of this and future research
- Failure to define community with explicit criteria
- Underdevelopment of community partnerships
- Community translation premature since intervention needs more work
- More attention needed to what will be left behind—continued impact of intervention, partnership and infrastructure
- Failure to articulate how the project will matter such as leading to best practice guidelines

Common Pitfalls in CBPR Proposals (2)

CBPR Specific Problems:

- *Absence of convincing rationale and plan for benefits of partnership (e.g., improved recruitment, retention, data collection, analysis/interpretation)*
- *Limitations in how commun input generated innovative approaches to overcoming CBPR challenges*
- *Insufficient documentation of prior CBPR training and experience of investigators*
- *Insufficient description of how commun partners being assured “a place at the table” enriches research process*
- *How will the CBPR approach enhance potential for dissemination of research findings and long term sustainability of research practices*

Common Pitfalls in CBPR Proposals (3)

CBPR Non-Specific Problems:

- Failure to demonstrate the applicability and generalizability of findings
- Feasibility problems re' assessment battery and model testing
- Lack of a theoretical framework for guiding the development of the program
- Absence of detail to execute project or its dissemination plans

Common Pitfalls in CBPR Proposals (4)

- Methodological flaws in testing of alternative models
- Paucity of preliminary studies to justify and substantiate the project
- Project not well integrated into the larger literature
- Underdeveloped data analytic plans

Ethical and Related Challenges in CBPR Proposals (1)

Ethical Challenges:

- **“Community-Driven” issue selection:**
Ensure that the research topic comes from the community
- **Insider-Outsider tensions & overcoming stereotypes:**
Ensure equitable benefits to all partners
- **Constraints on community involvement:**
Ensure that community desires w/ re’ to research design do not clash w/ outsiders view of good science
- **Dilemmas in the sharing and release of findings:**
Ensure that community has authentic role in deciding how data will be used
- **Challenges in the action dimensions of CBPR:**
Community may wish to move quickly but outside research partners may want to ‘put the brakes on’ until published

Ethical and Related Challenges in CBPR Proposals (2)

Partnership Challenges:

- Lack of trust and respect
- Inequitable distribution of power and control
- Conflicts over funding
- Conflicts associated with different emphases on process and task

Ethical and Related Challenges in CBPR Proposals (3)

Partnership Challenges:

- Time-consuming process
- Who represents the community and how is community defined
- Conflicts associated with differences in philosophy, priorities, assumptions, values, beliefs and language
- Plans to ensure sustaining impact of intervention and partnership over time

Ethical and Related Challenges in CBPR Proposals (4)

Methodological Challenges:

- Questions of scientific quality of research
- Proving intervention success
- Inability to fully specify all aspects of research up-front
- Seeking balance between research and action
- Time demands
- Interpreting and integrating data from multiple sources

Some Suggestions for Conducting CBPR(1)

- Jointly develop CBPR principles and what it means to have a “collaborative, equitable partnership” via informal democratic process and consensus decision-making
- Create a balance between time spent on process issues and tasks/products
- Select mutually defined priority issues, goals and objectives
- Include CBPR as a way to integrate meaningful questions for community—e.g., improve theoretical models explaining unmet need, non-compliance w/ treatment and poor service outcomes of disadvantaged racial/ethnic pops that require community input

Some Suggestions for Conducting CBPR(2)

- Focus on community strengths as well as problems
- Need to decide how community is defined, with explicit criteria, and who represents the community
 - Start small, involving a few highly regarded CBOs and community leaders within communities of identify
 - Obtain support and involve top leadership from partner organizations
 - Build on prior history of positive working relationships
- Reach a balance in the distribution of benefits and resources

Some Suggestions for Conducting CBPR(3)

- Need for expansion of funding programs to support innovative research methodologies, train outside the box and allow exploration of alternative research paradigms and atypical research strategies; training in team science
- Establish procedures for dissemination
- Emphasize mentoring, capacity building and establish/maintain infrastructure
- Conduct ongoing evaluation of the partnership process

Does CBPR work?

- Evidence is strongest that participation contributes to program improvement (through greater efficiency, sustainability and more equitable distribution of services)
- However, there is much weaker evidence that community participation by itself can create additional health benefits or that it increases intervention outcomes
- Some have suggested that empowerment can improve health outcomes among different subpopulations (e.g., youth at risk for HIV)

Therefore...

since CBPR is more of an approach than a method), a better (alternative) question might be, does CBPR:

- **Enhance community capacity?**
- **Facilitate intervention development?**
- **Identify mechanisms of disparities?**

Wallerstein, NB (2006). Using Community-Based Participatory Research to Address Health Disparities. *Health Promotion Practice*. Vol 7, No. 3, 312-323.

“In the process of enlightenment, there can only be participants.” (J. Habermas, 1974).

“The synergy that partners seek to achieve through collaboration is more than a mere exchange of resources. By combining the individual perspectives, resources, and skills of the partners, the group creates something new and valuable together—something that is greater than the sum of its parts.” (R.D. Lasker et al, 2001).

Continuing Our Dialogue

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