

Community-Based Participatory Research: Assessing the Evidence

Summary

Introduction

Community-based participatory research (CBPR) is an approach to health and environmental research meant to increase the value of studies for both researchers and the community being studied. This approach is particularly attractive for academics and public health professionals struggling to address the persistent problems of health care disparities in a variety of populations (identified by factors such as social or economic status, lack of health insurance, or membership in various racial and ethnic groups).¹⁻⁶ Few guidelines exist for evaluating CBPR grant proposals and determining what resources are required to promote successful community-based research efforts. Still less is known about the degree to which CBPR has been effective in sustaining long-term university–community partnerships and generating high-quality data to guide further research. Experts are becoming impatient with the gap between knowledge produced through conventional research and the translation of this research into interventions and policies to improve the health of various groups, especially minority communities and other disadvantaged populations.^{2,7-12}

Done properly, CBPR benefits community participants, health care practitioners, and researchers alike. CBPR creates bridges between scientists and communities, through the use of shared knowledge and valuable experiences.¹³⁻¹⁷ This collaboration further lends itself to the development of culturally appropriate measurement instruments, thus making projects more effective and efficient.^{18,19} Finally, CBPR establishes a mutual trust that enhances both the quantity and the quality of data collected.^{13,20-22} The ultimate benefit to emerge from such collaborations is a deeper understanding of a community's unique circumstances, and a more

accurate framework for testing and adapting best practices to the community's needs.^{2,13,15,18,23-29}

In 2001, the Agency for Healthcare Research and Quality (AHRQ), in collaboration with several Federal agencies and the W.K. Kellogg Foundation, convened a 2-day conference “to promote and support the use of CBPR, to develop strategies to advance CBPR, and to explore the use of CBPR as a resource for policymakers to help guide their program development.”³⁰ AHRQ organized the meeting specifically to address three key barriers to CBPR: (1) insufficient community incentives (staffing and resources) to play a partnership role in CBPR projects; (2) insufficient academic incentives (staffing and resources) for researchers to play a partnership role in CBPR projects; and (3) inadequate funding and insensitive funding mechanisms.³

The conference membership recommended an AHRQ-commissioned study of the existing evidence on the conduct and evaluation of CBPR, performed by one of the Agency's Evidence-based Practice Centers (EPCs). Accordingly, the Agency commissioned the RTI International–University of North Carolina (RTI-UNC) EPC to produce a systematic review and synthesis of the scientific literature regarding CBPR and its role in improving community health. Specifically, the EPC investigators were asked to consider four Key Questions (KQs):

KQ 1: What defines community-based participatory research?

KQ 2: How has CBPR been implemented to date, with regard to the quality of research methodology and community involvement?

* Drawing on this conference, AHRQ prepared a guide to community-based participatory research for community groups and the general public, *The Role of Community-Based Participatory Research: Creating Partnerships, Improving Health* (AHRQ Publication No. 03-0037, June 2003).



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KQ 3: *What is the evidence that CBPR efforts have resulted in the intended outcomes?*

KQ 4: *What criteria and processes should be used for review of CBPR in grant proposals?*

Methods

In 2002, the EPC convened a group of experts to provide early guidance for the investigation. The meeting participants included community research partners, academic researchers, and CBPR research financiers, bringing a diverse range of perspectives to the review. Feedback from the expert meeting substantially altered the researchers' search terms and their research questions.

Search Criteria

Articles considered for the EPC review included peer-reviewed reports of human studies, across all ages and both genders, conducted in English-speaking North America (U.S. and Canada), and published in the English language. The source language was limited to exclude from consideration international studies conducted in vastly different sociocultural and political climates. However, international publications that described the history and definition of CBPR were included. Editorials, letters, and commentaries were excluded from the analysis, as were articles in which information related to the key questions was not reported. The EPC staff limited its review to studies that included at least one community as a research collaborator and, therefore, excluded studies that involved only health agencies or other professional institutions in the research process.

Relevant Data Sources

For KQs 1 through 3, the EPC first searched standard electronic databases—e.g., MEDLINE[®], Cochrane Collaboration resources, PsycINFO, and Sociofile—using search terms based on the inclusion/exclusion criteria and additional key terms identified in the expert group meeting. The EPC researchers then consulted their Technical Expert Advisory Group (TEAG), regarding in-progress studies that had not been published. Key among the sources of information identified was a special CBPR issue of the *Journal of General Internal Medicine* (July 2003). The third level of the investigative process required EPC reviewers to perform hand searches of the reference lists of relevant articles, for the purpose of identifying additional articles to gain full information on particular studies. Unlike many research areas, searching the CBPR literature is labor- rather than computer-intensive.

For KQ 4, very few peer-reviewed articles directly addressed CBPR funding issues *per se*.³¹ Rather, the culled materials had a tendency to describe agency or foundation funding mechanisms used to support CBPR.^{32,33} Accordingly, the EPC researchers reviewed the Web sites of several organizations funding CBPR research and spoke with funding agency

representatives involved in the development of CBPR-related grants programs or their agencies' grant review process.

Data Collection and Analysis

Data was collected for KQs 1, 2, and 3 through the abstraction of relevant information from eligible articles and the creation of summary evidence tables presenting the key details and findings for the articles. The EPC paired trained abstractors with a senior reviewer, who used an analytic framework to guide development of abstraction tables. The EPC researchers used the same framework to rate the quality of both the primary research and primary community-based participation elements. They rated the quality of only those studies (often represented by a set of published articles) representative of a completed intervention study evaluation, or an observational study designed to permit extrapolation beyond the study population.

Results

The EPC researchers identified a total of 1408 abstracts with relevance to the four key questions. Of these, they retained and pulled 297 articles for complete review. Another 112 articles were excluded from this subset—typically because the study could not be considered CBPR. Ultimately, the EPC investigators reviewed 55 of the 185 retained articles for KQ 1 and 123 articles comprising 60 studies for KQs 2 and 3. [Full names and publications lists for the identified studies can be found in Table 4 of the complete Report.] The researchers reviewed 7 articles for KQ 4. A key limitation of using secondary and tertiary sources to identify CBPR studies is that the studies often do not identify themselves as CBPR.

KQ 1: Definition of Community-based Participatory Research

The EPC researchers sought to answer three important questions in their exploration of this topic:

- *What are the essential elements of CBPR?*
- *What are the “best practices” of CBPR, including the characteristics of successful investigator-community partnerships?*
- *What major outcomes are anticipated from both the research and community perspectives?*

The EPC researchers analyzed 55 conceptual articles (i.e., synthesizing the evolution of, values for, or lessons learned from collaborative research), in the process of writing a deliberately short working definition for CBPR. These articles each used terms common to, or similar to, CBPR. They originated with a variety of fields in the social and health sciences. Using these articles, the researchers were able to arrive at a definition they feel confident will serve the purposes of AHRQ, other Federal agencies supporting CBPR, and other interested parties and agencies:

Community-based participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.

To expand upon this definition, the authors further suggest that CBPR involves: (1) *co-learning and reciprocal transfer of expertise*, by all research partners, with particular emphasis on the issues that can be studied with CBPR methods; (2) *shared decisionmaking power*; and (3) *mutual ownership* of the processes and products of the research enterprise.

KQs 2 and 3: Intervention Studies and Outcomes

The EPC researchers found a striking degree of variability in the study designs, substantive concerns, and the extent of community involvement in CBPR studies. Thirty of the 60 studies relevant to these KQs included interventions, while the other 30 were noninterventional studies. For the purposes of this review, researchers defined an intervention as an organized and planned effort to change individual behavior, community norms or practices, organizational structure or policies, or environmental conditions.

KQ 2: Implementation of Community-based Participatory Research

Each of the 60 studies identified as CBPR resulted in an average of two publications. Thirty-five studies produced one published article each; not counting the East Baltimore Health Promotion Study—which lasted 17 years between the first publication and the last—the 24 studies with more than one publication each produced, on average, 3.5 articles over a period of about 2.5 years. The majority (63.6 percent) of the 55 studies giving information on their funding reported a single funding source, while a significant minority (32.7 percent) mentioned two funding sources, and a handful (3.7 percent) report more than two sources.

Quality of Research Methodology. Of the 60 CBPR studies, 30 included ongoing or completed interventions; of these, 12 evaluated the intervention and 18 either had not completed the intervention, or had not evaluated it fully. The remaining 30 studies did not have an intervention or did not report one.

Four of the 12 studies that implemented and evaluated interventions^{14,34-44} were randomized controlled trials (RCTs), and five were quasi-experimental studies. The three remaining studies had nonexperimental designs.

Of the 30 studies classified as noninterventional because they were neither designed with an explicit intervention nor did they undertake an evaluation of any intervention that might have resulted from their findings, 10 studies moved beyond problem identification to risk factor assessments,⁴⁵⁻⁵⁰ examining prevalence,^{51,52} and examining the impact of environmental or

policy change.^{53,54} Increasing community capacity or engendering empowerment as a byproduct of the collaboration, was the major objective in four of the projects.⁵⁵⁻⁵⁸

Community involvement in the research process. Sixteen studies documented the involvement of the community in making measurement instruments more culturally relevant, or mentioned field-testing their instruments to improve their reliability. Fourteen studies described the effort to build community partnerships through the use of baseline data, general findings, or process evaluation results. Many of the studies provided rich qualitative and quantitative data regarding the lengthy process of building partnerships between institutions and communities—although formal evaluation of this process was rare.

Regarding evidence in the published literature of the level of community involvement in the research process, 28 of 60 studies (47 percent) involved the community in helping to set priorities and generate hypotheses. The extent of community involvement, however, varied greatly among the studies. Community input was used in some studies to direct change or expand priorities while others used community involvement mainly to confirm their priorities.

Researchers many times took a lead role in proposal development, often applying for grants before the actual community involvement began. Fourteen studies mentioned community involvement in proposal development. Community involvement took place mainly in the form of advisory committees, but there were also examples of partnership steering committees in which community partners were involved as equal partners. In one turn of events, the community approached the researchers to initiate the proposal on the basis of the community's priorities and desired research.

Nineteen studies reported shared funding. Communities used funds mainly to pay for staffing. In one study, the community contributed some of the direct funding (taken from union funds) to maintain the research.

Twenty-eight studies described the active participation of the community in the study design and implementation. Fifty studies reported community involvement with respect to recruiting and participant retention. Contact with community members generally raised participation rates. Local staff helped to administer surveys and conduct interviews, and as survey helpers fluent in the languages of the target group.

Of 30 studies with a planned or implemented intervention, more than 90 percent (28 in all) reported community participation in the intervention design and implementation. Among the 30 studies without a planned intervention, 30 percent (10 studies) reported that community members had participated in the design of future interventions for the community, based on the study results.

Articles reviewed by the EPC investigators made little mention of the involvement of community partners in the data interpretation or manuscript preparation processes. Although

some papers included authors without academic degrees, the researchers could not draw firm conclusions about the level of participation by community partners.

The EPC researchers also identified those studies in which communities were involved in translating research findings into policy change. Three of the 60 studies reported demonstrable policy change in civic bodies, as a result of the intervention through the efforts of the community collaborators. Five studies brought about change in private institutions or at local levels through the efforts of community collaborators.

Thirteen studies reported on the sustainability of programs or interventions. An additional 28 studies detailed the integration or application of findings to achieve changes in health or other aspects of daily life. Some projects achieved temporary sustainability of programs through the acquisition of additional grants for further research or by attracting local funding.

KQ 3: Outcomes of Community-based Participatory Research

Improved Research Quality Outcomes. The investigators rated the 12 studies with completed interventions for research quality and for adherence to the principles of community participation. On a scale of 1 to 3, higher scores reflected better quality. The research quality scores reflected study design rigor, with experimental studies rating highest overall. Community participation scores, however, appeared less closely associated with study design. And while the scores on these two performance dimensions are not directly comparable, the average research quality scores ranged from 1.5 to 2.8 with a mean of 2.3, while the community participation quality scores ranged from 1.6 to 3.0 with a mean of 2.2.

When the EPC researchers looked at the influence of community involvement on the quality of interventional studies, they discovered 11 of the 12 completed intervention studies had reported enhanced intervention quality. Just two studies reported improved outcomes, while eight noted enhanced recruitment efforts, four reported improved research methods and dissemination, and three described improved descriptive measures. Very little evidence of diminished research quality resulting from CBPR was reported.

Community and Research Capacity. Of the 60 studies reviewed, 47 reported improved community involvement, including additional grant funding and job creation, as an outcome associated with the study. The authors—typically academics—generally focused on the increased capacity of the participant community, rather than that of the research community.

Health Outcomes. Among the 12 studies evaluating completed interventions that play a role in health outcomes, two dealt with physiologic health outcomes, three with cancer screening behavior, and four addressed other behavioral changes (including alcohol consumption, immunization rates, and safer sex behavior). Finally, three studies measured the impact of the

intervention on emotional support, empowerment, and employee well-being.

Given the highly varied health outcomes, measurement strategies, and intervention approaches used, the EPC researchers were unable to perform a direct comparison of studies and their relative impact on health outcomes. Moreover, an absence of cost-effectiveness data precluded any comparison of outcomes from CBPR studies and those of more traditional research studies.

KQ 4: Funding Criteria for Community-based Participatory Research

AHRQ asked the EPC investigators to address several specific questions about CBPR funding, drawing on the lessons learned through the synthesis of the literature on the first three key questions. Specifically:

1. *What current approaches are being used by funders in their efforts to solicit and review CBPR grant proposals?*
2. *What criteria should high quality grant applications possess?*
3. *What guidance can be offered to funding organizations and CBPR applicants?*
4. *Who should be involved in the review process? What should be the role of the community?*

Current Approaches by Funders. The Centers for Disease Control and Prevention and the National Institute of Environmental Health Sciences have been at the forefront of Federal CBPR funding to date. Specific initiatives by these agencies include many of the EPC-reviewed studies. Interest in funding CBPR at the Federal level is growing, given the recent creation of an Interagency Working Group for Community-based Participatory Research. This group has begun assembling information on existing funding mechanisms for CBPR.

Discussions with individuals from the NIH and CDC tasked with generating requests for research proposals on specific topics (Requests for Applications, or RFAs) and administering the review process underscored the need for brief guidance materials (fact sheets) about CBPR for reviewers less familiar with this approach. Guidelines for individuals writing RFAs designed to encourage CBPR submissions and documents providing guidance for researchers submitting CBPR proposals also were recommended.

Criteria for Applications. According to the details of conversations between researchers and funders, the process of obtaining funding for CBPR projects through conventional review mechanisms can be a difficult one. This is often because reviewers are less familiar with (and perhaps even skeptical about) the possibility of integrating high-quality conventional research within the framework of a CBPR collaboration. The EPC researchers identified relatively few high-quality completed interventions or observational studies, relative to what appears to be many excellent collaborations based on CBPR principles.

Guidance for Funding Organizations and Applicants.

The researchers created three concise documents providing guidance to funding organizations, reviewers, and applicants, based on the EPC's review, discussions with Federal funding sources, reviews of funding agency Web sites, and the funding criteria outlined above. The EPC elected to employ the same review criteria often used by agencies within the U.S. Department of Health and Human Services in the development of these prototype guideline documents; these criteria are both standardized and rigorous. These documents (CBPR Exhibits 1, 2, and 3) are available on the RTI Web site (<http://www.rti.org>).

Involvement in the Review Process. Discussions with funding providers and their review of the literature led EPC investigators to recommend the inclusion of academic experts for the content area, and for CBPR methods, on project application review panels. Moreover, they recommended involving individuals with expertise in both arenas. The researchers further suggested the potential value of including community representatives, but emphasized the need to orient and structure the review panels to immediately and effectively tap into the expertise of the community representatives.

Discussion

Implementing CBPR

Research Quality. Authors of interventional studies (whether traditional or CBPR) often must publish their findings and study methodology in separate articles. The nature of CBPR further compounds this fragmentation when years of partnership development and collaboration must be distilled to few words in a small number of journals willing to publish this more descriptive science. This may be why information regarding the implementation of CBPR, both in terms of community participation and the research, often was missing in the EPC-reviewed articles.

A limited number of studies representing a complete and fully evaluated intervention—an observational study or an epidemiologic study that can be generalized beyond the participants involved—have been published to date. Limiting factors appear to be the categorical nature of most Federal funding, funding period length and flexibility, and the page limitations of journals.

There was little evidence to indicate that high-quality scores in community collaboration are associated with low-quality research scores. Recent special journal issues focusing on CBPR have led a number of publications to implement high-quality research methods. CBPR funding initiatives originating with Federal agencies have the potential to do the same.

Level of Community Involvement. Community involvement varied in different stages of the research. There was strong involvement in recruiting study participants, designing and implementing the intervention, and interpreting findings. Many authors argued that community involvement (especially in these areas) leads to greater participation rates, increased

external validity, decreased loss of follow-up, and increased individual and community capacity. The disadvantages of community involvement were not frequently reported, but they may include the introduction of selection bias (bias in recruitment), decreased (and sometimes an absence of) randomization, and the potential selection of highly motivated intervention groups not representative of the broader population.

Achieving Intended Outcomes

Improving Research Quality. In CBPR, researchers must work with the community to select and justify the strongest possible research methods, while balancing research rigor with their responsiveness to the community. The researchers must credit community members with the ability to understand complex research challenges, if presented clearly and thoughtfully. One of the many benefits of making research partners of community members is that they begin to see the long-term gains associated with research, in comparison to the relatively short-term nuisance of data collection activities.

Enhancing Community Capacity. Enhanced community capacity was rarely mentioned in the EPC's review of the literature as an explicit goal of CBPR projects. Rather, it was mentioned in descriptions of the collaborative process and was clearly considered to be a critical component. Studies were much more likely to report capacity building in the community, than in the cadre of researchers or their institutions. Perhaps a true indicator of investigator appreciation for CBPR might be published study results that include a discussion of capacity-building efforts on the part of the researchers.

Improving Health Outcomes. Among the limited number of fully evaluated, complete interventions that were identified, the stronger or more consistently positive health outcomes generally were found in the higher quality research designs. This should convince CBPR research partnerships to pay adequate attention to the "R" component of CBPR.

Given the long-term nature of true CBPR efforts, individual and community capacity-building efforts ultimately may result in positive health outcomes that have little or nothing to do with those targeted in the initial study. None of the studies reviewed could accurately predict such long-term and indirect potential benefits of CBPR.

Funding Issues

Because CBPR is a potential approach to translational research, the EPC researchers have suggested using peer review groups with a background in translational research or research dissemination to consider the merits of grant proposals for this type of research. Conversely, peer review by conventional mechanisms rather than special emphasis panels has the potential to expand the options for funding CBPR efforts, while at the same time educating other scientists on the potential rigor and "added value" of CBPR. A proposal based

on CBPR should not simply describe CBPR criteria—it should also discuss the potential benefits for the research quality and for the community.

Future Research

In many areas of health promotion and 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 to health promotion through its ability to mobilize community action. Continued efforts aimed at achieving the best possible balance between research methodologies and community collaboration are critical to advancing the field.

The EPC investigators anticipate a significant increase in high-quality CBPR coverage in the near future, due in part to a number of recent Federal initiatives funding CBPR projects and a willingness on the part of respected journals to publish the findings. Along with proposed CBPR proposal-writing and peer-review guidelines, the investigators also have suggested that recommendations may be needed to improve the quality of CBPR study reports. These guidelines would reflect the increasing rigor required of authors in the evidence-based practice field, while at the same time acknowledging the unique situation facing those researchers who are balancing research rigor with a commitment to community collaboration.

Availability of the Full Report

The full evidence report used to create this summary was prepared for the Agency for Healthcare Research and Quality by the RTI–University of North Carolina Evidence-based Practice Center under Contract No. 290-02-0016. It is expected to be available late in the summer of 2004. At that time, printed copies may be obtained free of charge from the AHRQ Publications Clearinghouse by calling (800)-358-9295. Inquiries should include a request for Evidence Report/Technology Assessment No. 99, *Community-based Participatory Research: Assessing the Evidence*. In addition, Internet users will be able to access the report and this summary online through AHRQ’s Website at www.ahrq.gov.

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