

# **Community-Based Participatory Research: A Summary of the Evidence**

**Summary**

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## **Community-Based Participatory Research: A Summary of the Evidence**

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# Summary

## Introduction

Community-based participatory research (CBPR), as an approach meant to enhance both research and community outcomes, has received increased attention as academic and public health communities struggle to address the persistent problems of disparities in the use of health care and in health outcomes for several populations, including those identified by diagnosis, socioeconomic status, lack of health insurance, and membership in various racial and ethnic groups.<sup>1-6</sup> Few guidelines exist as to how CBPR proposals should be evaluated and what resources are required to promote successful efforts in such research. Even less is known about the degree to which a CBPR approach has been effective in sustaining long-term academic-community partnerships and generating high-quality data to guide the research agenda. Experts are becoming impatient with the gap between knowledge produced through conventional research and translation of this research into interventions and policies to improve the health of various groups, including communities of color and other disadvantaged populations.<sup>2,7-12</sup>

Done properly, CBPR benefits community participants, practitioners, and researchers alike. CBPR creates bridges between scientists and communities, allowing both groups to gain knowledge and experience.<sup>13-17</sup> This collaboration assists in developing culturally appropriate measurement instruments, thus making projects more effective and efficient.<sup>18,19</sup> Finally, CBPR establishes a level of trust that enhances both the quantity and the quality of data collected.<sup>13,20-22</sup> The ultimate benefit is the prospect of examining a community's unique circumstances to test and adapt best practices to its own needs.<sup>2,13,15,18,23-29</sup>

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.”<sup>30</sup> AHRQ organized the meeting specifically to address three key barriers to CBPR: (1) poor community incentives and capacity to be partners in CBPR projects; (2) poor academic incentives and capacity for researchers to act as partners in CBPR projects; and (3) inadequate funding and insensitive funding mechanisms.

Conference participants, through working groups and extensive discussion, produced three sets of recommendations, aimed at funders, community members, and academics. The information generated was intended “to describe the current context or environment for CBPR, to develop strategies to promote CBPR, and to provide funding organizations with input from communities as they work together to improve the health and well-being of those in communities.”<sup>30</sup> Among the recommendations was a request that an AHRQ Evidence-based Practice Center (EPC) synthesize evidence on the conduct and evaluation of CBPR.

AHRQ awarded this evidence report to the RTI International – University of North Carolina (RTI-UNC EPC). Our systematic review consolidates and analyzes the body of literature that has been produced to date on CBPR in several areas relating to key questions (KQ ) focused on improving health in communities. Specifically, the RTI-UNC EPC was asked to consider:

**Note:** Appendixes and Evidence Tables cited in this report are provided electronically at <http://www.ahrq.gov/clinic/epcindex.htm>.

- 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?
- 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 RTI-UNC EPC convened a group of experts to provide early guidance on our work. Meeting participants brought diverse perspectives to this review from their work as community research partners, academic researchers, and funders of CBPR research.

### Inclusion and Exclusion Criteria

We included peer-reviewed published reports of human studies, all ages and both sexes, in the English language, conducted in English-speaking North America (U.S. and Canada); systematically reviewing empirical studies conducted in vastly different sociocultural and political climates would have exceeded the scope of this effort. We did include international publications for describing the history and definition of CBPR. Exclusion criteria (apart from the obverse of the above) included editorials, letters, and commentaries; articles that did not report information related to the key questions; and studies that did not provide sufficient data for us to abstract. We limited our 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 KQ 1 through 3, we first searched standard electronic databases such as MEDLINE<sup>®</sup>, Cochrane Collaboration resources, Psycinfo, and Sociofile using specified search terms. Based on our inclusion/exclusion criteria and additional key terms identified by our expert meeting attendees, we generated a list of Medical Subject Heading (MeSH) search terms and included these in our systematic search strategy. Second, we consulted with our Technical Expert Advisory Group (TEAG) about studies that were under way but not yet published. Key among the sources of information identified was the special CBPR issue of the *Journal of General Internal Medicine* (July 2003). Third, we conducted hand searches of the reference lists of relevant articles. In conducting systematic reviews, we often find it necessary to pull additional articles to gain full information about a particular study. The CBPR literature represents an extreme case of this situation.

For KQ 4, very few peer-reviewed articles directly addressed CBPR funding issues *per se*;<sup>31</sup> rather, the materials we found tended to describe funding mechanisms for CBPR, such as the Urban Research Centers funded by the Centers for Disease Control and Prevention (CDC)<sup>32-36</sup> and the Environmental Justice funding mechanism of the National Institute of Environmental Health Sciences (NIEHS).<sup>37</sup> Hence, we also reviewed the Web sites for several funding agencies supporting CBPR research. We also talked with representatives from the Interagency Working

Group for Community-Based Participatory Research and with individuals at the CDC and National Institutes for Health (NIH) who were involved with developing CBPR Requests for Applications (RFAs) or organizing their agencies' grant review process more generally.

## **Literature Search Results**

Across the four key questions, we identified a total of 1408 abstracts for review. Of these, we retained and pulled 297 articles for complete review. Of these, we excluded 112; the most common reason for exclusion was that the study could not be considered CBPR. Ultimately, of the 185 articles retained, we reviewed 55 for KQ 1. For KQ 2 and 3, we reviewed 123 articles that constituted 60 studies. For KQ 4, we reviewed 7 articles. A key limitation of employing secondary and tertiary sources to identify CBPR studies is that they are often not self-identified as CBPR.

## **Data Collection and Assessment**

For KQ 1, 2, and 3, data collection involved abstracting relevant information from the eligible articles and generating summary evidence tables that present the key details and findings for the articles. We paired trained abstractors with a senior reviewer. We employed an analytic framework to guide development of abstraction tables, which we designed to approximate the final evidence tables as closely as possible. We also used the framework to guide the quality rating system (described below). Both the abstraction tables and quality ratings were divided into primary research and primary community-based participatory elements.

For KQ 2 and 3, because of the multiplicity of articles from a single study, the first step in data collection involved grouping articles by study. Once we had compiled a complete set of articles pertaining to a single study, abstractors keyed the data into an evidence table. The senior reviewer paired with the abstractor performed quality control assessments by reviewing each evidence table against the original articles and making revisions as needed.

## **Grading the Strength of the Evidence**

We developed four quality rating forms to grade the strength of the evidence and the degree to which the research in question implemented CBPR principles. Given the significant diversity of CBPR research, including outcomes, research methodology, and measures, we elected to rate the quality of only those studies (often represented by a set of published articles) that represented either a completed evaluation of an intervention study (12) or an observational study designed to permit extrapolation beyond the immediate study population (3).

# Results

## Literature Identified

### KQ 1: Definition of Community-Based Participatory Research

In exploring this topic, we sought to answer three important questions:

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

We retained and reviewed 55 peer-reviewed articles that were conceptual; that is, they synthesized the evolution of, values for, or lessons learned from collaborative research. These articles all used CBPR or similar terms, such as action research, collaborative community action research, community-centered praxis, participatory action research, participatory evaluation, and participatory research. The articles came from the fields of anthropology, community development, community psychology, disability research, environmental health, health education, health sociology, injury research, mental health, nursing, organization development, patient care, and reproductive health.

### KQ 2 and 3: Intervention Studies and Outcomes

As expected, we found a striking degree of variability in the study designs, substantive concerns, and extent of community involvement of CBPR studies. Of the 60 studies relevant to KQ 2 and 3, 30 listed interventions and 30 were noninterventional studies. We defined an intervention as an organized and planned effort to change behavior among individuals, communities’ norms or practices, organizational structure or policies, or environmental conditions.

### KQ 4: Funding Criteria for Community-Based Participatory Research

Based on our discussions with the TEAG and AHRQ, we understood our task to be primarily one of synthesizing our findings for the purpose of guiding future applications (proposal writers), reviewers, and agencies toward submitting and funding the best possible CBPR research. To this end, we used the findings for KQ 2 and 3 to identify the strengths and weaknesses of currently funded CBPR research and highlight some of the challenges that CBPR researchers face.



# Findings

## KQ 1: Definition of Community-Based Participatory Research

We scrutinized 55 articles in depth to gain a comprehensive view of the nature, principles, and practical aspects of CBPR. From this analysis, we arrived at a workable and deliberately short definition of CBPR that guided our work and that, we believe, can serve the purposes of AHRQ and other federal agencies that extensively support CBPR, and other interested parties and agencies.

Our summative definition is as follows: *CBPR 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 this definition, we conclude that CBPR is about: (1) *co-learning and reciprocal transfer of expertise*, by all research partners, about the issues of concern and, within those, the issues that can be studied with CBPR methods; (2) *sharing decisionmaking power*; and (3) *mutual ownership* of the processes and products of the research enterprise. The end result is incorporating the knowledge gained with taking action or effecting social change to improve health and well-being of community members.

## KQ 2: Implementation of Community-Based Participatory Research

To answer KQ 2, we drew from the 60 studies identified as CBPR. We found an average of two publications per study: 35 studies published only one article, but the remaining 25 studies produced, on average, 3.5 articles. 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 covered a period of about 2.5 years from the first to the last publication.

Journal restrictions on the length of the article, in addition to multiple topics emerging from CBPR collaborations, are likely to contribute to the multiplicity of articles in these instances. Also, CBPR collaborations may take longer, in general terms, than some other types of research, and thus more time to publish results for CBPR effort

We were able to determine funding source for 55 of the 60 studies. The majority (53 percent) of these reported a single funding source, but a significant minority (33 percent) mentioned at least two funding sources.

**Quality of Research Methodology.** We were best able to evaluate research methodology by distinguishing among three categories of studies. Of 60 studies, 30 were completed interventions or ongoing interventions; of these, 12 evaluated the intervention and 18 had either not completed the intervention, or not evaluated it fully. The remaining 30 studies either did not have an intervention or did not report one.

*Studies that implemented and evaluated interventions.* Of the 12 studies in this category, four were randomized controlled trials (RCTs); they included Communities Mobilizing for Change on Alcohol,<sup>38-43</sup> East Baltimore Health Promotion,<sup>44-47</sup> Health is Gold!,<sup>48</sup> and the Sierra

Stanford Partnership.<sup>49,50</sup> Five of the 12 were quasi-experimental studies; these included HIV Testing and Counseling for Latina Women,<sup>51-55</sup> Internet Access and Empowerment,<sup>56</sup> the Korean Breast and Cervical Cancer Screening Intervention,<sup>57-59</sup> the Okanagan Diabetes Project,<sup>60</sup> and the Wai'anae Cancer Research Project.<sup>61-63</sup>

The three studies with nonexperimental designs included the New York Immunization Project,<sup>64</sup> the Stress and Wellness Project,<sup>14,65-68</sup> and Women Dedicated to Demolishing Denial: HIV Risk Reduction for Lesbians and Bisexual Women.<sup>69,70</sup> One study used a one-group pretest and posttest design (New York Immunization); another involved data collection throughout the intervention (Women Dedicated to Demolishing HIV Denial); and the third (the Stress and Wellness Project) started with a nonexperimental design but, because of changes in operations at the study site, eventually became a natural experiment comparing two sites, with pretest and posttest data.

Quantitative data collections predominated. Five studies used a combination of qualitative and quantitative data collection methods (HIV Testing and Counseling for Latina Women, Internet Access and Empowerment, the Okanagan Diabetes Project, Wai'anae Cancer Research Project, and the Stress and Wellness Project), and one used only qualitative methods (Women Dedicated to Demolishing HIV Denial). Two studies mentioned blinded data collection (the Sierra Stanford Partnership and the Stress and Wellness Project).

*Interventions either not completed or not fully evaluated.* This group of studies illustrates the long-term nature of much CBPR work and the fact that many studies require several publications issued over several years to report the full findings of the project. Of the 18 ongoing interventions, four were part of ongoing experimental designs (Community Action Against Asthma,<sup>71-73</sup> PRAISE!,<sup>74,75</sup> Seattle King County Healthy Homes Project,<sup>76</sup> and Seattle Vaccine<sup>77</sup>). One was intended to be a quasi-experimental design (TEAL<sup>78</sup>). Finally, 13 were nonexperimental designs (Elderly in Need,<sup>79,80</sup> East Side Village Health Worker Partnership,<sup>81-91</sup> Haida Gwaii Diabetes Project,<sup>92</sup> Healthy Homes, Healthy Child,<sup>93-95</sup> Kahnawake,<sup>96-100</sup> La Vida,<sup>101</sup> Mom Empowerment, Too!,<sup>102</sup> the Nuclear Risk Management for Native Communities Project,<sup>103</sup> Preventing Agricultural Chemical Exposure in North Carolina Farmworkers (PACE),<sup>104,105</sup> The Partners for Improved Nutrition and Health Project (PINAH),<sup>106</sup> Preventing Halloween Arson,<sup>107</sup> Survival Guide,<sup>108,109</sup> and Women and Heart Disease.<sup>110</sup>

*Noninterventional studies.* We identified 30 studies that we classified as noninterventional because they neither were designed with an explicit intervention nor undertook an evaluation of any intervention that might have resulted from their findings. Of the 30 noninterventional studies, 27 were nonexperimental and primarily exploratory in nature. The other 3 were observational studies designed to permit extrapolation to individuals beyond the study population (African Americans Building a Legacy of Health,<sup>111</sup> Hospice Access and Use by African-Americans,<sup>112</sup> and Oregon Migrant Farm Workers<sup>113,114</sup>). The purpose of these studies varied; several had multiple objectives. We classified studies according to what appeared to be their primary objective in the literature available to us. More than half the studies were predominantly concerned with understanding the problem at hand (16 of 30). Of these 16 studies, 2 focused on identifying health problems (Poultry Slaughterhouse Study<sup>115,116</sup> and HERE<sup>117</sup>); 8 were explorations of health-related knowledge, attitudes, and practices (James Bay Cree Diabetes,<sup>118</sup> Together for Agricultural Safety (TAS) Project,<sup>119</sup> Perspectives of Pregnant and Postpartum Latino Women on Diabetes, Physical Activity, and Health,<sup>120</sup> The Native Hawaiian Smokers Survey,<sup>121</sup> Controlling Pesticide Exposure to Children of Farmworkers,<sup>122</sup> Hospice Access and

Use by African-Americans,<sup>112</sup> Diabetes in East Harlem,<sup>123</sup> and Disability Community<sup>124</sup>); and 6 were intended to serve as a needs assessment involving community members in identifying health issues, concerns, and determinants that might ultimately be used to develop an intervention study or to inform community action (Aboriginal Grandmothers,<sup>125,126</sup> Positively Fit,<sup>127</sup> Bingham,<sup>128</sup> Housing Options,<sup>129</sup> Madison County,<sup>130</sup> Participatory Action Research for Community Health Promotion<sup>131</sup>).

Ten studies moved beyond problem identification. Of these, six assessed factors influencing risk (Oregon Migrant Farm Workers,<sup>113</sup> Chinese American Elderly with Osteoporosis,<sup>132</sup> Community Health and Environment Program,<sup>133-135</sup> Ethnocultural Communities Facing AIDS,<sup>136-142</sup> The Harlem Birth Right Project<sup>143</sup> and Welcome Home Ministries<sup>144,145</sup>); two examined prevalence (The Glades Health Survey,<sup>146</sup> West Harlem Environmental Action [WE ACT]<sup>147,148</sup>); and two examined the impact of environmental or policy change (EJS,<sup>149,150</sup> Evaluation of the Blended Funding Project<sup>151</sup>). Although most CBPR studies are designed to increase community capacity or engender empowerment as a byproduct of the collaboration, four projects described this as the major objective of the study (African Americans Building a Legacy of Health,<sup>111</sup> Healthy Neighborhoods,<sup>152,153</sup> Participatory Action Research for Hmong Women,<sup>154</sup> South Asian Women<sup>155</sup>).

Of the 29 studies in this category that provided information on data collection methods, the majority used qualitative methods as either the sole method or in combination with quantitative methods (62 percent). In 12 projects, the sole data collection method was qualitative. In another 6 studies, the investigators combined qualitative and quantitative methods. In another 11 studies (38 percent) the investigators reported using only quantitative methods.

**Community involvement in the research process.** Considering the variety of potential avenues for community participation, 16 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 that described the effort to build community partnerships presented baseline data, general findings, or only process evaluation results. The rest primarily described either the research process or the effort to build a community-research collaboration. Finally, many of these studies provided rich qualitative and quantitative data about the lengthy process of partnership development between institutions and communities. The articles described how the collaborative process benefited study design, data collection, and participant recruitment or retention, although only rarely did they include a formal evaluation of this process.

We reviewed all 60 studies to record evidence of the level of community involvement in the research process. As with other sections of this review, our findings are limited by the information available in the published literature. Twenty-eight studies brought the community into phases relating to setting priorities and generating hypotheses. Often, community-based organizations were already concerned with an issue before researchers approached the community. Sometimes residents needed to be recruited to form a community advisory committee. The extent of community involvement varied greatly. Some studies changed or expanded priorities based on community input; others mainly used community involvement to confirm priorities. One article reported a community organization that took the lead role, approaching the researchers about its priorities and desired research.

Researchers usually took the lead role in proposal development, often applying for grants before the actual community involvement started. 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 instance, the community approached the researchers to initiate the proposal.

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 study design and study implementation. Some communities served in the form of advisory boards or steering committees to discuss possible challenges to study implementation; one community proposed appropriate study designs to researchers; one steered investigators away from potentially unsuccessful designs. In several cases, community involvement tried to ease recruitment and study implementation by using local staff to administer surveys or interviews or to act as survey helpers who were fluent in the languages of the target group.

Fifty studies reported community involvement with respect to recruiting and retaining study participants. Contact with community members generally raised participation rates. Community advisory boards or community-based organizations were often actively involved in the recruitment of participants.

Communities frequently participated in intervention design and implementation. Of 30 studies with a planned or implemented intervention, more than 90 percent (28 studies) reported community involvement in intervention design and implementation. Among the 30 studies without a planned intervention (fully evaluated or otherwise), 10 (30 percent) reported that communities helped design interventions for the community based on the results.

The articles we reviewed said very little about whether community partners were involved with data interpretation or manuscript preparation. Although some papers included authors without academic degrees, we could not draw firm conclusions about the level of participation by community partners.

We reviewed the studies to identify those in which communities were involved in translating research findings into demonstrable policy change, either in civic bodies or at private institutions and local levels. 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. The Environmental Justice Study led to a presentation of findings to the House Agricultural Committee of the North Carolina General Assembly, followed by subsequent changes in policy. As a result of the Communities Mobilizing for Change on Alcohol study, policies were altered to reduce youth access to alcohol through changes in procedures and practices in the communities via alcohol merchants, law enforcement and criminal justice, community events, hotels, media, treatment agencies, and religious venues. Participatory Action Research for Community Health Promotion, partly through supporting data from its survey, prompted the city council in the community to pass an ordinance to create nonsmoking areas. Five studies brought about change in private institutions or 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 that affect health or other aspects of daily life. Some projects achieved temporary sustainability of programs by acquiring additional grants for further research or by attracting local funding.

### **KQ 3: Outcomes of Community-Based Participatory Research**

**Improved Research Quality Outcomes.** We scored the 12 studies with completed interventions in terms of two outcome evaluations: average scores for research quality and for adherence to the principles of community participation. Higher scores reflect better quality. The average scores could range from 1 to 3. Although the scores on these two 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 an average of 2.2.

As would be expected, research quality scores reflected research design rigor. Experimental studies averaged 2.7; quasi-experimental, 2.2; one-group pretest and posttest design, 1.9; and the one nonexperimental intervention study, 1.5. Community participation scores appeared less closely associated with study design, with the experimental studies averaging 2.3; quasi-experimental, 2.2; one-group and posttest design, 2.3; and the nonexperimental study, 1.95.

We also conducted quality ratings on the three observational studies that we deemed were of sufficiently strong design to permit generalizability to a population beyond that of the study sample. Many observational studies reviewed served primarily as baseline data for a community assessment or an intervention study with no attempt at representative sampling techniques, thus were not included in the quality ratings. We used slightly different criteria for research quality ratings with the observational studies, primarily related to the lack of an intervention. Research quality rating scores for the three observational studies were 1.4, 2.6 and 2.1, with community participation scores of 1.6, 2.6, and 2.0, respectively.

Quality rating scores for research elements primarily reflect internal and external validity. Recognizing that RCTs are not always feasible or ethically appropriate in CBPR where one group would be denied an intervention, we rated the intervention studies based on specific criteria reflecting reliability and validity rather than requiring a randomized controlled trial for the highest quality rating. While the four experimental completed intervention studies were all RCTs, a study using group assignment with careful matching of intervention and comparison groups would also have been included. Studies were downgraded, for example, if the study population differed significantly from the population to which findings were generalized, if there was significant loss to followup, or if the intervention and comparison groups were not comparable demographically. For observational studies, we downgraded those that failed to adequately justify their sampling procedure or the control of confounders.

In abstracting data from these studies, we documented evidence of either enhanced or diminished research quality attributable to the CBPR method; we focused on the categories of methodology, measures, recruitment, intervention, analysis, dissemination, and outcomes. Of the 12 completed intervention studies, 11 reported enhanced intervention quality related to community involvement. Only two studies reported improved outcomes related to CBPR. Eight noted enhanced recruitment, four reported improved research methods and dissemination, and

three described improved measures. Very little evidence of diminished research quality resulting from CBPR was reported. One study suggested possible recruitment bias and another reported that the CBPR approach pulled staff away from intervention delivery, thus reducing the exposure to the intervention.

**Community and Research Capacity.** Of the 60 studies in this review, 47 reported improved community capacity as an outcome associated with the study. Generally, authors focused on the greater capacity of the participant community rather than that of the research community, possibly reflecting the perspectives of authors who were primarily academic researchers. Nine studies documented the improved capacity of the researchers and research organization derived from collaboration with the community.

Seven studies mentioned the communities' enhanced capacity to create change. Increases in community capacity would happen either directly through the research results or indirectly through the process of participating in the research.

Studies demonstrated enhanced community capacity in numerous ways. Additional grant funding obtained by the community was one such outcome. Another positive result was the jobs that the collaboration created. Partnership and coalition development were other beneficial outcomes. Finally, numerous studies mentioned the communities' enhanced capacity to conduct research, either in combination with other outcomes of community capacity or as the sole evidence of enhanced community capacity.

**Health Outcomes.** Among the 12 studies evaluating completed interventions addressing health outcomes, 2 dealt with physiologic health outcomes, 3 with cancer screening behavior, and 4 with other behavior changes such as alcohol consumption, immunization rates, and safer sex behavior. Finally, 3 studies measured the impact of the intervention on psychosocial outcomes such as emotional support, empowerment, and employee well-being.

The four RCTs reviewed yielded some modest positive effects; eight non-RCTs showed more mixed results. Given the highly varied health outcomes, measurement strategies, and intervention approaches used, comparing studies to assess relative impact on health outcomes was not possible. Cost-effectiveness data would have allowed us to compare similar outcomes from CBPR studies and more traditional research studies, but no study provided such data.

From our review we were unable to determine whether the modest positive findings reported could be attributed to CBPR methods. Several authors mentioned positive effects of their CBPR approaches on research quality and participation rates, but we could not ascertain whether these benefits directly improved study outcomes relative to other research approaches.

## **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 synthesis of the literature on the first three key questions. Specifically:

1. What are current approaches by funders to soliciting and reviewing CBPR grant proposals?
2. What criteria should high quality grant applications meet?
3. What guidance can be offered to funding organizations and applicants?

4. Who should be involved in the review process? What should be the role of the community?

**Current Approaches by Funders.** The CDC and NIEHS have been at the forefront of federal funding for CBPR to date. Specific initiatives by these agencies include many of the studies we reviewed. The considerable interest at the federal level in funding CBPR research is further evidenced by the recent creation of an Interagency Working Group for Community-Based Participatory Research. This group has begun to assemble information about existing funding mechanisms for CBPR.

Because CBPR is a potential approach to translational research, study sections designated for this purpose are particularly appropriate. This would include, for example, Demonstration and Education Research within the National Heart, Lung, and Blood Institute and Translational Research within the National Institute of Diabetes and Digestive and Kidney Diseases. The National Cancer Institute now has a study section to review dissemination proposals, which have similarities to translational research and would also likely benefit from a CBPR approach

Discussions with individuals from the NIH and CDC who are involved with generating RFAs and administering the review process highlighted the need for brief guidance materials about CBPR for reviewers less familiar with this approach. They recommended fact sheets that could be distributed between sessions to standing panels or with other orientation materials for special emphasis panels. Also recommended were guidelines for those writing RFAs designed to encourage CBPR submissions and offer guidance for researchers submitting CBPR proposals.

**Criteria for Applications.** Obtaining funding for CBPR through conventional review mechanisms is a significant challenge because reviewers may be less familiar with and perhaps even skeptical about CBPR. However, review by conventional mechanisms rather than special emphasis panels has the potential to expand the options for funding CBPR efforts, and this mechanism can educate other scientists about the potential rigor and “added value” of CBPR.

Researchers applying for funds to support CBPR often fail to address adequately the criteria for high-quality *conventional* research. We identified relatively few high-quality completed interventions or observational studies relative to what appears to be many excellent collaborations based on CBPR principles. This mismatch raises the question of whether researchers assume that effectively combining high-quality conventional research with CBPR collaborations is not possible. If so, they may simply choose not to embark on such ventures.

In addition to the conventional research proposal review criteria, a proposal based on CBPR should clearly describe the added value that this approach brings, particularly when reviewers can be assumed to be unfamiliar with CBPR. The proposal should not simply describe CBPR criteria; it should also discuss the potential benefits for both research quality and the community.

**Guidance for Funding Organizations and Applicants.** Based on our review, discussion with federal funders, review of funding agency Web sites, and the criteria for funding outlined above, we created three concise documents that provide guidance to funding organizations, reviewers, and applicants. The grant proposal and review process is somewhat standardized across the U.S. Department of Health and Human Services (using the PHS-398 package); in addition, these agencies are likely to involve the most rigorous review process. Thus, in developing these prototype guideline documents, we elected to use the review criteria generally used by these agencies. The three documents are *CBPR Reviewer and Applicant Guidelines*

(Exhibit 1), *CBPR Reviewer Checklist* (Exhibit 2), and *CBPR Requests for Applications and Peer Review* (Exhibit 3).

**Involvement in the Review Process.** Our discussions with funders and review of the literature led us to recommend that review panels include academic experts in the content area and in CBPR methods and that the panels also involve individuals who have expertise in both arenas. Our discussions regarding how community members should be involved prompted the recommendation that care must be taken to orient and structure panels carefully if the expertise of community members is to be tapped effectively.

## Discussion

### Implementing CBPR

**Research Quality.** Publishing intervention research (conducted by either CBPR or less participatory methods) faces challenges related to page limitations of journals. Authors of such studies must often publish their findings and study methodology in separate pieces. The nature of CBPR compounds this fragmentation further when years of partnership development and collaboration must be reported in few words and in a small number of journals willing to accept this more descriptive science. Perhaps as a result, information about the implementation of CBPR, both from the community participation and the research perspectives was often missing.

To date, a limited number of studies have been published that represent a complete and fully evaluated intervention or an observational or epidemiologic study that can be generalized beyond the participants involved in an intervention study (baseline data). Limiting factors appear to be the categorical nature of most federal funding: limitations on funding length and flexibility and page limitations of journals. Despite frequent suggestions to the contrary, we found little evidence that high-quality scores in community collaboration are associated with low-quality scores for research. Recent special issues for journals focusing on CBPR have resulted in a number of publications using high-quality research methods. CBPR funding initiatives from federal agencies have the potential to do the same.

**Level of Community Involvement.** Community involvement extended through all areas of research with variable involvement in different stages. We saw 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 followup, and increased individual and community capacity. Disadvantages of such methods were not frequently reported, but they may include some loss of internal validity, often through introduction of selection bias (recruitment), lack or sometimes even loss of randomization if contamination occurs, or 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 that balance research rigor and responsiveness to the community. To strengthen proposals and manuscripts, CBPR researchers should present arguments in their proposals that identify the potential costs and benefits of a variety of different approaches from both the research and community perspectives. In addition, researchers must credit community members with the ability to understand complex research challenges if they are presented clearly and thoughtfully. One of the many benefits of involving community members as research partners is that they begin to see the long-term gains associated with research while coming to understand the relatively short-term bother of the data collection activities.

**Enhancing Community Capacity.** In our review of CBPR research, enhanced community capacity was rarely mentioned 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 on the part of the community than on the part of the researchers or their institutions.

In our review of the definitional literature, development of individual investigator and research institution capacity to interact more collaboratively with the community on research issues is a significant expectation of CBPR. It may be difficult for researchers, who are the traditionally designated “experts” in conventional academic-community partnerships, to view themselves as learning from their community partners. Perhaps a true indication of whether investigators appreciate CBPR is when published study results discuss capacity building on the part of the researchers.

**Improving Health Outcomes.** Among the limited number of fully evaluated, complete interventions identified the stronger or more consistent positive health outcomes were generally found in the higher quality research designs. This should serve as an incentive to CBPR research partnerships to pay adequate attention to the “R” component of CBPR.

Given the long-term nature of true CBPR efforts, the potential scope of related health outcomes perhaps cannot be realized from one 5-year study focused on a specific chronic illness. Building individual and community capacity may result in future positive health outcomes that have little or nothing to do with those initially targeted by the study. None of the studies we reviewed could have captured such long-term and indirect potential benefits of CBPR.

**Criteria and Processes for Reviewing CBPR Proposals.** With the abundance of interest in funding CBPR efforts, it is critical to understand what we have learned to this point and how this can be applied to improving this field of research in the future. Guidelines for applicants and reviewers are also essential, as are recommendations for funding agencies interested in supporting this type of work.

## Future Research

In many areas of health promotion and disease prevention, researchers and community advocates alike are beginning to focus their efforts further “upstream” on the so-called

socioecologic model, which means a greater emphasis on policy and environmental changes that facilitate health-promoting choices at the individual level. CBPR is well positioned to address such upstream approaches to health promotion through its ability to mobilize community action. Continuing to seek the best possible balance between research methodology and community collaboration is critical if the field is to move forward.

New guidelines from international groups provide clear instructions on how randomized controlled trials (CONSORT) and observational studies (MOOSE) should be reported. Systematic reviews such as these are frequently hampered by the lack of standardization in the peer-reviewed literature, leading to many studies being left out or an inability to draw useful conclusions about a particular field of research.

Because of a number of recent initiatives by federal agencies to fund CBPR and by respected journals to publish its findings, we anticipate a significant increase in high-quality CBPR publications in the near future. Just as we have proposed guidelines for the CBPR proposal-writing and peer-review process, perhaps recommendations are needed for improving the quality of reports for CBPR studies. These guidelines would reflect the increasing rigor required of authors in the evidence-based practice field while recognizing the unique situation facing researchers who are balancing research rigor with commitment to community collaboration. For CBPR to gain more credibility and receive research dollars, we must hold ourselves to the highest possible standards from both perspectives.

## **Exhibit 1. CBPR reviewer and applicant guidelines**

### **CBPR efforts that involve community and academic partners as collaborators have the potential to improve the quality and impact of research by**

1. more effectively focusing the research questions on health issues of greatest relevance to the communities at highest risk;
2. enhancing recruitment and retention efforts by increasing community buy-in and trust;
3. enhancing the reliability and validity of measurement (particularly survey) instruments through in-depth and honest feedback during instrument development and pretesting;
4. improving data collection through increased response rates and decreased social desirability response patterns;
5. increasing relevance of intervention approaches and thus likelihood for success
6. increasing accuracy and culturally sensitive interpretation of findings;
7. facilitating more effective dissemination of research findings;
8. increasing the potential for translation of evidence-based research into sustainable community change that can be disseminated more broadly.

A strong proposal based on CBPR principles will clearly describe how the potential benefits described above will be combined with strong scientific rationale and methodology as follows:

#### **Significance**

- Demonstrate the extent to which achievement of the aims will advance scientific knowledge and/or improve the methods or intervention approaches used within the field.
- Describe the potential impact of the study on reducing health disparities through increased knowledge and/or social change resulting from the community partnership.
- Convey the perceived importance and relevance of the research questions and proposed study to community partners and thus the likelihood for increased buy-in and participation.

#### **Innovation**

- Present specific aims that are original and innovative.
- Describe clearly how the proposal employs novel concepts, approaches, or methods.
- Demonstrate how the proposed project challenges existing paradigms or develops new methodologies.
- Describe how innovative ideas resulted from community participation in developing the research questions, methods, and/or intervention approaches.
- Discuss how community input generated innovative approaches to overcoming research challenges.

#### **Approach**

- Present a conceptual framework, design, methods, and analyses that are adequately developed and appropriate to the aims of the project.
- Describe the degree to which community input has or will enhance the conceptualization, design, methods, and analyses.
- Present strong arguments for the proposed study design as the best possible balance of scientific rigor, implementation constraints, and ethical treatment of community partners.

**Exhibit 1. CBPR reviewer and applicant guidelines (continued)**

- Provide the rationale for how the community partnership is expected to enhance recruitment, retention, measurement design, data collection, and analysis/interpretation.
- Discuss the plan for how the CBPR process will facilitate dissemination and translation of findings.
- Describe potential limitations of the study design and/or CBPR approach and how you will address these concerns.

**Translation (when relevant)**

- Demonstrate how the proposal will apply evidence-based research in the community setting to translate research findings into practice.
- Describe how the CBPR approach will enhance the potential for dissemination and long-term sustainability.

**Investigators**

- Provide information indicating that the training, qualifications, experience and commitment of the investigators are appropriate and well suited to the project.
- Document the experience of the investigators with prior CBPR efforts.
- Indicate the degree to which and in what way university and community partners have collaborated in the past.
- Describe the way in which community partners will be assured “a place at the table.”
- Indicate the specific expertise and strengths to be contributed by community partners.
- Include a representative community advisory board/steering committee to guide the design and conduct of the study.

**Environment**

- Describe the degree to which the institutional and scientific environment in which the work will be done contributes to the probability of success.
- Indicate whether the proposed study takes advantage of unique features of the scientific, institutional, or community environment or employs useful collaborative arrangements.
- Provide evidence of institutional and community support through letters and descriptions of prior collaboration.

**Budget**

- Discuss how direct costs are consistent with the proposed methods, specific aims, and CBPR approach.
- Provide good documentation for compensation to study participants and community partners in terms of ethical rationale and enhanced recruitment, retention, and participation.
- Provide justification for resources applied to enhancing the research capacity of community members (such as interviewer training) while improving your response rate.
- Provide justification for infrastructure support to community organizations.
- Create a mechanism whereby community organization can serve as the lead fiduciary agency.

Source: Adapted from “Instructions for Preparing Written Evaluations for R18 Applications” from the National Institute of Diabetes, Digestive, and Kidney Diseases

**Exhibit 2. CBPR reviewer checklist**

Evidence in specific proposal sections should demonstrate combined strength in research methodology and community collaboration, according to the items in the sections below.

<b>Significance</b>
<ul style="list-style-type: none"> <li>❑ Reflects a synthesis of the latest epidemiological and clinical literature regarding the health problem identified and the existing barriers to change.</li> <li>❑ Presents a clear and up-to-date understanding of CBPR literature and principles.</li> <li>❑ Reflects a realistic understanding of the potential limitations of CBPR (such as significant time requirements subjectivity associated with community data collectors).</li> <li>❑ Provides evidence (through letters of support, survey results, description of prior CBPR work in “preliminary studies”) that the health problem addressed is significant to community participants and thus likely to enhance their participation.</li> <li>❑ Makes a convincing argument that a CBPR collaboration will increase the likelihood of future translation or dissemination through existing community channels, thus leaving something in place when the research ends.</li> </ul>
<b>Innovation</b>
<ul style="list-style-type: none"> <li>❑ Reflects creative problem solving to achieve the strongest possible blend of rigorous research methodology, feasibility, and community sensitivity. Presents the strengths and limitations of multiple possible approaches and a final plan.</li> <li>❑ Builds on identified community strengths, such as existing organizations and networks, cultural beliefs, and political will.</li> <li>❑ Reflects community input in the design of rigorous data collection approaches that are also acceptable to participants and respectful of their culture, time, and resources.</li> <li>❑ Includes embedded substudies designed to assess the degree to which CBPR methods enhance or diminish research quality.</li> </ul>
<b>Approach</b>
<ul style="list-style-type: none"> <li>❑ Reflects community involvement in all phases of the research effort (community steering committee, representatives on the proposal team, feedback mechanisms) and provides structures for shared decisionmaking.</li> <li>❑ Suggests an effort to provide research collaborators and participants with the necessary information and guidance about the research process to make informed choices regarding their involvement and contribution (in-service training, materials written in lay language).</li> <li>❑ Builds on the knowledge and strengths of community collaborators in the areas of participant recruitment, measurement instrument development and testing, intervention development, and data collection (formative work, hiring community research assistants, involving local practitioners).</li> <li>❑ Recognizes potential limitations of this approach and takes steps to address them (blinding interviewers about study status of subjects, plans for issues of confidentiality and research ethics, draws on research staff from outside the community to avoid bias when needed).</li> <li>❑ Reflects a blend of flexibility and rigor in implementing sound research methods that respect participants’ interests.</li> <li>❑ Measures include socioeconomic determinants of health, and interventions reflect an understanding of these influences.</li> <li>❑ Intervention studies include cost-effectiveness analysis and feasibility assessment to determine long-term sustainability within the research community and/or other groups.</li> <li>❑ Proposes presenting study results to members of the community (following rules of confidentiality) and seeking their input regarding interpretation, presentation, and dissemination of the data.</li> <li>❑ Includes process measures to document and understand the partnership dynamics and the feasibility and acceptability of intervention, measurement, and data collection approaches.</li> </ul>

**Exhibit 2. CBPR reviewer checklist (continued)**

<b>Translation (when relevant)</b>
<ul style="list-style-type: none"> <li>❑ Describes mechanisms and approaches to building individual and community capacity that remains with the community after the researchers are gone and increases the likelihood of achieving health improvements as a result of the research (e.g., training, hiring for research jobs, leadership roles, presentation of findings, infrastructure building, proposal writing).</li> <li>❑ Considers carefully the approach to dissemination of research findings while respecting confidentiality. Proposes sharing results with research participants and designing dissemination strategies involving community partners in the academic meetings, academics at community meetings, and print dissemination approaches for both academic and community-level distribution (newsletters, videos, lay publications, TV, and radio).</li> <li>❑ Includes plans to assess longer-term sustainability of interventions evaluated as part of the study.</li> </ul>
<b>Investigators</b>
<ul style="list-style-type: none"> <li>❑ Includes community members on the list of key personnel and provides biographical information about leaderships' roles and responsibilities in the community.</li> <li>❑ Ensures that biosketches and descriptions of academic partners reflect prior collaborative research involvement with communities (beyond simply research "in" the community).</li> <li>❑ Includes, in the preliminary studies section, relevant work of the academic as well as community partners.</li> </ul>
<b>Environment</b>
<ul style="list-style-type: none"> <li>❑ Includes a section on the community "environment" in terms of individual and institutional support (availability of space and facilities for data collection including blood specimens, meeting rooms for interventions and community advisory board/steering committee meetings).</li> <li>❑ Describes the political environment as either a support or challenge related to sensitive research topics such as HIV-AIDS, smoking, or domestic violence.</li> <li>❑ Indicates the degree to which resources obtained for the proposal would be used to enhance the research environment within the community if this is lacking (e.g., computers for data collection, refrigerator for blood specimens).</li> </ul>
<b>Budget and Timeline</b>
<ul style="list-style-type: none"> <li>❑ Reflects the resources and time needed to develop or enhance community partnerships.</li> <li>❑ Includes resources and a strong rationale for expenses related to recruitment, retention, and partnership building while respecting the cost of research to participants and community partners (food, travel, lodging, meeting room rental, office supplies for community-based research staff, reimbursement or incentives for lay health advisors).</li> <li>❑ Includes and justifies the cost of training and materials to institutionalize interventions or initiate efforts by the community to address policy and environmental change as a result of research findings.</li> </ul>

### Exhibit 3. CBPR requests for applications and peer review

## Recommendations for constructing requests for applications and designing the review process to enhance the potential for strong and responsive applications employing principles of community-based participatory research (CBPR).

### Requests for Applications

#### Resources to Guide the Process

- Provide links and references describing the fundamental principles and rationale for CBPR
  - <http://lgreen.net/guidelines.html>
  - <http://www.sph.umich.edu/chsp/>
  - <http://www.ccpb.info/Others>
  - Israel Schulz, Parker, 1998\*
  - Viswanathan, Ammerman, Eng, et al., forthcoming<sup>†</sup>
- Provide links and references describing the proposal-writing process in language understandable by community partners. (sources for this?)
- List contact information for individuals in your agency who can answer questions and provide additional resources regarding CBPR

#### RFA Text and Budgetary Guidance

- Use language in the RFA text that is understandable by both academic and community partners.
- Structure the RFA to include a planning grant or partnership development period  
Possible approaches:
  - Implement a 1 year planning grant to strengthen or facilitate the development of community partnerships and participatory proposal development
    - those receiving planning grants are not guaranteed a full grant
    - success in partnership development is a prerequisite for obtaining full funding
  - Include planning and partnership development time on the front end of longer term funding mechanism
- Provide review criteria that
  - Emphasize the importance of high-quality research design and measurement combined with adherence to the principles of CBPR
  - Include methodological flexibility – study design and measurement methods that retain the ability to draw unbiased conclusions from the research while accommodating practicality and ethical treatment of the community.
- Create budget guidelines that are flexible enough to accommodate:
  - community organizations as lead fiduciary agent
  - subcontracts to community-based organizations
  - hiring community-based research assistant staff and covering office expenses
  - participant and community participation incentives and reimbursement such as timely payment for study participation, food for community events
  - shared decisionmaking between the university and community agencies
  - the longer timelines required for CBPR

\* Israel BA, Schulz AJ, Parker EA, et al. Review of community-based research: assessing partnership approaches to improve public health. *Annu Rev Public Health* 1998; 19:173-202.

<sup>†</sup> Viswanathan M, Ammerman A, Eng E, et al., Community-Based Participatory Research: A Summary of the Evidence, RTI International-University of North Carolina Evidence-Based Practice Center, Contract No. 290-02-0016. Forthcoming.

## Peer Review

- **Assemble a review panel that includes**
  - academicians with expertise and experience in the content area
  - academicians with expertise and experience in CBPR and the content area
  - some role for community members with experience in CBPR and/or content area
- **Provide guidance and training to reviewers regarding CBPR principles and methodology**
  - for standing study sections, provide links for Web-based materials between study section meetings
  - for special emphasis or ad hoc review committees, distribute information on CBPR principles and review criteria when proposals are mailed.
  - conduct a conference call with review panelists after receiving proposals to assure their understanding of CBPR and address related questions
  - talk at greater length; have an in-depth discussion with the Chair of the study section or review panel to assure that they understand CBPR principles
- **If review panels include academicians and community representatives:**
  - Hold a meeting immediately prior to beginning before the review meeting panel discussions to assure everyone understands their roles and is comfortable with their responsibilities
  - Involve community representatives in the review discussion but do not assign them as a primary or secondary reviewer
  - Require PIs to supply a “lay” version of the abstract as well as the conventional abstract
  - Request that primary reviewers take responsibility for soliciting useful feedback from the community representative
  - Require that the summary report include a section addressing comments from the community representative
- **Provide reviewers with guidelines and checklists** that combine conventional proposal review criteria along with criteria for assessing the application of CBPR methods
- **Encourage discussions** among the review panel members at the time of the review that weigh the relative strengths and weaknesses of conventional research approaches (such as randomized controlled trials) against modifications that are more responsive to community concerns (such as delayed intervention control)
- **Create scoring criteria** that evaluate:
  - Adherence to sound study design, measurement, and analysis principles
  - Adherence to the principles and best practices of CBPR
- **Provide feedback to applicants** addressing both research methodology and CBPR principles



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