Chapter 4. Discussion

Defining Community-based Participatory Research

As described in Chapter 3, to address Key Question 1 of this systematic review, we scrutinized 55 articles in depth to gain a comprehensive view of the nature, principles, and practical aspects of community-based participatory research (CBPR). We compared and contrasted this material in terms of seven main steps and stages of CBPR, as set against issues of the essential elements and best practices for the conduct of CBPR. From this analysis, we arrived at a workable definition of CBPR that guided our work and that, we believe, can serve the purposes of the Agency for Healthcare Research and Quality (AHRQ), sponsor of this evidence report, other Federal agencies that extensively support CBPR, and other interested parties and agencies.

Specifically, we propose that 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. This is a deliberately short definition that, by itself, does not completely convey the critical philosophical or practical aspects of successful CBPR. Thus, we suggested that the concept should be extended to emphasize three main ideas. First, CBPR is about "co-learning" by both researchers and community collaborators and "mutual transfer" of expertise and insights into the issues of concern and, within those, the issues that can be studied with CBPR methods. Second, it is about "sharing in decisionmaking." Finally, CBPR is about "mutual ownership" of the processes and products of the research enterprise.

A significant implication of this definition is the need to understand the intended outcomes of CBPR activities. The goal is improving the health and well-being of members of the community, however defined for a given research project, by means of taking actions that bring about intended change and minimize unintended negative consequences of such change.

Implementing CBPR

Quality of Research Methodology

An inherent challenge faced by anyone trying to evaluate the quality and impact of CBPR methodology is the fact that being true to the methods makes it nearly impossible to compare CBPR rigorously to research carried out with more traditional research methods. The problem begins early in the process in that the purest form of CBPR requires that the community identify the health problem to be addressed. One could not readily compare the process and outcome of a study for which the community chooses diabetes as a research focus and the researchers choose HIV/AIDS.

Although in theory one could preselect a study outcome and measure and then conduct a two-arm trial randomizing half the participants to a CBPR approach and half to traditional

research methodologies, the two approaches would almost certainly yield different sets of measures, interventions, and recruitment and retentions strategies, leaving very little for comparison other than the final outcome measure. One would be left wondering whether the outcomes achieved were potentially biased by different factors in each study that could be the result of the research method used, such as interviews conducted by individuals hired from the community in the CBPR arm as compared to interviews done by graduate students in the traditional arm.

In the absence of randomized trials comparing CBPR with non-CBPR approaches, we are left with trying to draw conclusions from what investigators report in published journal articles. We have found that publication of intervention research (conducted by either CBPR or traditional methods) is associated with significant challenges related to page limitations of journals. Authors of such studies must often publish their findings and study methodology in separate pieces. This problem is further compounded for CBPR work; researchers must report years of partnership development and collaboration in very few words and in a small number of journals willing to accept this more descriptive science. As a result, we found that articles lacked information about the implementation of CBPR, from both the community participation and the research perspectives.

In our review, we were careful to assess research quality based on factors such as internal and external validity rather than a strict adherence to traditional study designs. For example, rather than specifying that a randomized controlled trial (RCT) is the highest quality study design, we assessed the degree to which the study sample was representative of the larger population to which generalizations would be made, whether intervention and comparison groups were comparable, the quality of the measures, and loss to followup. Study designs that included a delayed intervention control group intended to provide benefit to those randomized to the control condition were rated as very high-quality studies. Similarly, studies that gave thoughtful attention to the identification of a nonrandomized comparison that preserved internal validity while responding to community concerns were also given high marks.

To date, a limited number of CBPR studies have been published that represent a complete and fully evaluated intervention or an observational/epidemiologic study that can be generalized beyond the participants involved in an intervention study (baseline data). Recent special issues for journals focusing on CBPR have reported on studies with high-quality research methods, as with the July 2003 issue of the *Journal of General Internal Medicine*. Other journals (including the *American Journal of Public Health* and the *Journal of Interprofessional Care*) have issued similar calls for CBPR articles, but these occurred after our evidence review period. Much of the research reported in these special issues was generated as a result of studies funded through the Centers for Disease Control and Prevention (CDC), the National Institute for Environmental Health Sciences (NIEHS), and several foundations. As funding agencies and high-quality peer-reviewed journals begin to recognize the legitimacy and potential value of CBPR, these steps offer further encouragement to researchers combining both excellent research methods and adherence to the principles of CBPR.

Although the potential for trade-offs between addressing community concerns about research and maintaining high-quality study designs has been cited as a possible challenge to high-quality research,[2,58] our review does not suggest a strong trend in the direction of solid community-based

participatory methods combined with weak research design or measurement (Table 6). Similarly, the strongest research methods do not appear to be combined with weaker community participation elements. Again, owing at least in part to page limitations in those journals publishing rigorous experimental research, researchers tend not to describe fully their research methodology, adherence to CBPR principles, and the degree to which the collaboration may have benefited or threatened the research quality. Future CBPR researchers should consider identifying creative approaches to condensing this information in tabular format or making it available on the Web.

Most of the studies we reviewed were nonexperimental in design; only a limited number included any sort of intervention. When multiple papers were published about a single study, we combined the information in a single table row of our evidence tables and treated the data as a single unit. We did not inflate the relative number of nonexperimental studies by the spread of content across several articles. Many papers described the partnership development process and reported on formative data related to their processes and assessments of community concerns. In our view, many of the nonexperimental studies had been funded with small grants to develop partnerships around an identified health issue that did not provide sufficient resources to conduct an intervention or rigorous evaluation.

We also speculate that few larger intervention and/or experimental trials were funded in the past because review panels were not receptive to a CBPR approach. To the traditional researcher, asking study "subjects" to identify the focus of research, help design the intervention, and provide feedback on measurement instruments and data analysis might be viewed as scientific heresy. At the same time, researchers skilled in community collaboration may or may not be equally skilled in using rigorous research methodology and thus able to convince reviewers of the strength of the complete CBPR approach.

Additional possible explanations for the relative lack of completed evaluations of CBPR interventions is the "lack of fit" between the dynamics of true community collaborations and the peer-review funding approach to setting research priorities, maintaining timelines, and exercising budgetary control. Partnership development between communities and researchers takes time; if such work is to be truly community-guided, then it requires a different way of thinking about choosing research topics and allocating funding.

CDC and the National Institutes of Health (NIH) are major sources of health-related funding. Both agencies are divided into institutes and centers primarily related to specific disease entities, such as diabetes, cardiovascular disease, and HIV/AIDS. For the most part, these agency divisions generate funding opportunities and review proposals. This results in what is sometimes referred to as "categorical funding," which ultimately leads to putting researchers in the position of choosing a health issue and then looking around for a community where this topic can be studied. With the exception of some foundations, such as the W.K. Kellogg Foundation with the Community-based Public Health Initiative, and Federal agencies, such as the CDC with the Urban Research Center Initiative and more recently the CBPR initiative, few funding opportunities allow the flexibility of research partners selecting the focus of their research based on concerns identified within the community.

Length of funding is also an issue. In true CBPR, by the time the partnership has formed and the health outcome is identified, time in the funding cycle (usually a maximum of 5 years) is

generally inadequate to implement and complete a well-developed intervention and rigorous evaluation. Several solutions have been proposed. Israel and colleagues recommend the use of planning grants to facilitate partnership development and identification of the research focus.[226] The planning grant could be a "stand-alone" funding option or linked to a larger followup funding opportunity. The CDC REACH (Racial and Ethnic Approaches to Community Health) Initiative, for example, makes followup funding for longer-term work contingent on successful partnership development and issue identification. The CDC's Community-based Participatory Prevention Research effort requires the community-university research collaborative to demonstrate an existing track record before applying. This approach rewards researchers who choose to become involved in community collaborations before the potential for funding becomes an incentive.

Finally, budgetary restrictions may inhibit the generation of high-quality CBPR. Perhaps more important than the total amount is flexibility in budget management and expenditures. As communities receive an increasing number of requests to participate in research projects, often receiving little direct benefit in return (such as an epidemiologic study where risks are identified but no intervention is delivered in return), they are understandably demanding more involvement regarding the decisions about expenditures. For example, funds could be used to hire graduate students to conduct telephone surveys or to hire and train community members who are currently unemployed, thus infusing funds directly into the community while building capacity among community members. Budgetary restrictions (such as no overhead dollars to be spent on food) that may be an irritation to academics can have more serious consequences for research in the community, where food is considered an essential component of social interaction and serves as an incentive or an acknowledgment for research participation. Indirect expenses, in general, represent a disparity between universities and the communities, where the academic institution receives substantial overhead, but few indirect costs of the community organization are covered.

Level of Community Involvement

In our review, community involvement extended through all areas of research, although the extent of involvement varied by the stage of the research. The strongest involvement was in recruitment of study participants, design and implementation of the intervention, and interpretation of findings. Many authors argued that community involvement, especially in these areas, led to greater participation rates, increased external validity, decreased loss to followup, and increased individual and community capacity.

Disadvantages to such methods were not frequently reported. They may include some loss of internal validity, often through introduction of selection bias (recruitment), and lack or sometimes even loss of randomization if contamination occurs as community members become more knowledgeable and share intervention strategies with control or comparison groups. Disadvantages may also inclue highly motivated intervention groups not representative of the broader population and possible biased interpretations of findings.

In many cases, distinguishing between advantages or disadvantages associated with CBPR can be difficult. For example, on the whole, community mobilization can yield high and sustained attendance rates at intervention group sessions but also produce some "spillover effect"

in the control group. Whether this is, on balance, a good or bad thing for the research process is open to debate.

Our review suggests that hypothesis generation and proposal development remained mainly in the hands of researchers. Most studies involved some form of community advisory boards that worked closely with the researchers in setting priorities, developing interventions, and assuring a culturally appropriate approach. Only a few, however, involved a steering committee or decisionmaking board that actually took an active lead role.

If this leadership pattern could be attributed to the community's lack of decisionmaking power and experience or lack of ownership of the research, the publications we reviewed did not make it clear. Some articles addressed the persistent challenge for researchers to maintain scientific validity and to share ownership with community groups and address participant interests. In one diet and cancer study (PRAISE!), researchers scrambled to create a non-nutrition intervention for the delayed intervention control group when it appeared that this group was so enthused about the project that they intended to create and implement their own nutrition intervention early in the project. Other researchers reported mid-course adjustments in the intervention or measurement approach based on input from the community.

Some studies reported that application of findings influenced policy changes that led to a sustainable improvement for the community. Others received further funding that was obtained by the community. Apart from these obvious successes, some studies suggested that empowerment of the community was a positive result of participation in the research.

Achieving Intended Outcomes

Improving Research Quality

To achieve the highest research quality, researchers must select the strongest possible study design, measurement approach, data collection plan, and analysis strategy to address their specific research question or specific aims. If community input suggests that an RCT to test a diabetes intervention would be unacceptable because the control group would receive no benefits, it is incumbent on the researcher to work with the community to select and justify the strongest possible alternative design, such as a delayed intervention control. The research partner must present arguments in the proposal that identify the potential costs and benefits of a variety of different approaches from both the research and community perspectives.

In addition, researchers must give community members credit for the ability to understand complex research challenges if they present the issues 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 — for example, improved intervention approaches, increased potential for funding and dissemination, "ammunition" to advocate for effective policy changes — even as they come to understand the relatively short-term bother of the data collection activities themselves (e.g., blood draws, long surveys). This can have a positive effect on the immediate study and on the potential for study participants to become involved with future research efforts.

Given the substantial number of good-quality but incomplete CBPR intervention studies we identified, an increasing number of initiatives to fund CBPR work, and journal editors giving special attention to this research, the number of high-quality CBPR publications is likely to rise significantly in the next few years.

Improving Community Capacity

Authors of the studies we reviewed here rarely brought up enhanced community capacity as an explicit goal of a CBPR project. Rather, they mentioned it in descriptions of the collaborative process and clearly considered it to be a critical component. Studies were much more likely to report capacity building on the part of the community rather than on the part of the researchers or their institutions.

In our review of the definitional literature, however, development of the capacity of individual investigators and research institutions to interact more collaboratively with the community on research issues is a significant expectation of CBPR. Researchers, who are the traditionally designated "experts" in conventional academic-community partnerships, may find it hard to view themselves as learning from their community partners. When published studies results discuss capacity building on the part of the researchers, we may rightly conclude that such learning has taken place.

Improving Health Outcomes

Among the limited number of fully evaluated complete interventions that we located for our review, the stronger or more consistent positive health outcomes were generally found in the higher-quality research designs. This could 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, one could argue that the potential scope of related health outcomes cannot be realized from one 5-year study focused on a specific chronic illness. If a CBPR effort successfully builds individual and community capacity, future benefits may include improved lifestyle habits, increased institutional responsiveness to workers' health concerns, or changes in policy that facilitate a healthier environment. Associated positive health outcomes might have 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.

Planning Future Research

Criteria and Processes for Reviewing CBPR Proposals

Although our review focused on published CBPR papers rather than grant proposals, it provided some insight into the quality of research that has been funded. We were somewhat surprised by the limited number of high-quality completed intervention and observational studies identified in our review. Because we included only completed interventions and epidemiologic

studies in our quality rating system, we may have missed some high-quality research projects focused on formative data collection or cross-sectional survey findings that did not meet these criteria.

We have discussed some potential reasons for the limited number of high-quality published studies describing completed interventions. They included unfamiliarity with CBPR principles or skepticism about involving research participants in the research enterprise, challenges of developing a research partnership and completing a study within the traditional funding frameworks, and a focus of many reports on the development of research partnerships rather than outcomes. As described in the next section, we have reason to believe that this number of completed projects will grow in the near future because of several initiatives promoting the funding and publication of CBPR.

With the abundance of interest in funding CBPR efforts, understanding what we have learned to this point and how this can be applied to improving this field of research in the future is critical. Guidelines for applicants and reviewers are also essential, as are recommendations for funding agencies interested in supporting this type of work. Indeed, our review suggests that the stronger studies were somewhat more likely to be funded by Federal agencies with more stringent review processes than, for example, State or community-level organizations.

If we are to continue in our efforts to understand the quality and impact of CBPR, funders must structure their Requests for Applications (RFAs) to elicit responsive applications adhering to CBPR principles, and reviewers must be adequately familiar with the nuances and potential added value of CBPR to identify proposals with the greatest potential to move this field forward. Exhibits 1 through 3 (in Appendix E[*]) offer guidelines to support this effort.

Challenges of the Literature Review

As with many systematic efforts to review the literature, this one was hampered by our inability to initially narrow the scope of the literature using existing Medical Subject Headings (MeSH) terms or key words. MEDLINE® searches for CBPR articles are particularly challenging because the literature is newly emerging and the MeSH indexing is not yet adequate for the task. We considered many terms while constructing our searches (Table 10). Terms with asterisks occur frequently in the relevant citations and CBPR literature, and terms in quotes are key words, not MeSH terms.

Searching MEDLINE® and combining these three concepts yielded more than 1,300 citations. These multiple searches yielded numerous articles of varying relevance; moreover, formal MEDLINE® searches did not always identify highly relevant articles. When we probed, we could find no consistent coding. Thus, we supplemented these searches with citation searches in previously identified articles and with recommendations from experts in the field.

As CBPR becomes better recognized and understood, the MeSH indexing should become more sensitive. We recommend building a uniform set of MeSH headings to describe CBPR and encouraging journal editors to suggest the use of these terms as appropriate.

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

Future Growth of CBPR

Based on several developments in CBPR research uncovered in our review, we believe that the number of high-quality CBPR studies published is likely to increase substantially in the near term. First, NIEHS continues to fund proposals emphasizing CBPR and environmental justice. Second, NIEHS hosted a conference in 2000 on successful models of CBPR to "expand the acceptance, use, and applicability of CBPR as a valuable tool in improving the public health of the nation" (p. 1), followed by a report titled *Successful Models of Community-Based Participatory Research.*"[227] Third, AHRQ convened a CBPR planning conference in 2001; AHRQ also initiated the EXCEDE program—90 national leaders interested in advancing CBPR. Fourth, the Journ*al of General Internal Medicine* published a special issue on CBPR in 2003 (funded by AHRQ), as did the *American Journal of Public Health*, also in 2003. Finally, the *Journal of Interprofessional Care* will sponsor a CBPR theme issue in 2004. Fifth, the CDC, through the Urban Research Centers and the Prevention Research Centers, continues to fund this type of research. Sixth, the W.K. Kellogg Foundation has increased support to train Community Health Scholars, with an emphasis on CBPR methods. Seventh, a CDC initiative (totalling $13 million) seeks to support "multi-disciplinary, multi-level, participatory research that will enhance the capacity of communities and population groups to address health promotion and the prevention of disease, disability, and injury"; 26 proposals for 3-year projects have been funded. Eighth, formation of a Federal interagency workgroup for CBPR[60] will strengthen communication among Federal agencies with an interest in supporting CBPR processes.[228] Ninth, an Environmental Health Perspectives' Supplement, "Advancing Environmental Justice Through Community-Based Participatory Research.[229] Finally, a report by the Community-Campus Partnership for Health, "Developing and Sustaining Community-University Partnerships for Health Research: Infrastructure Requirements."[230]

Given the predicted increase in high-quality CBPR publications in the near future, we recommend that AHRQ or another agency committee sponsor an updated evidence review of CBPR within a few years to assess the development of this field and to refine, insofar as necessary, our proposed guidelines for proposal development and review.

Environmental and Policy Change

In many areas of health promotion and disease prevention, researchers and community activists alike are beginning to focus their efforts further "upstream" on the socioecologic model, which means placing a greater emphasis on policy and environmental change that facilitate health-promoting choices at the individual level. The belief is that individuals currently facing a "toxic environment" related to air quality, availability of healthy foods, opportunities for physical activity, and ease of access to alcohol and cigarettes may be better served by community-level change than by intensive efforts aimed at individual behavior change.

CBPR fits well with this trend toward "upstream" approaches to health promotion through its ability to mobilize community action. Although some approaches to environmental and policy changes require State or national legislative decisions, many other environmental enhancements can occur through micro-level policy change within the community or workplace. For example, some CBPR efforts were able to identify workplace health and safety issues of great concern to

the workers, form working groups, and begin to address some of the issues (the Stress and Wellness and Poultry Slaughterhouse projects illustrate these steps; see Table 8 in Chapter 3 for the full set of references). Better funding for this research effort might have allowed for a stronger study design able to demonstrate effectiveness.

Conventional and CBPR researchers alike face many challenges in the area of study design and measurement as we move our research upstream. However, CBPR approaches to community collaborations are well positioned to engage communities and achieve the desired changes. Seeking the best possible balance between research methodology and community collaboration is critical to move the field forward.

Improving the Quality of CBPR Reports

New guidelines from international groups provide clear instructions on how randomized controlled trials (CONSORT) and observational studies (MOOSE) should be reported.[231,232] Systematic reviews such as this one 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. If studies are incompletely or inaccurately documented, their quality rating is likely to be downgraded (fairly or not).[233,234]

Just as we have proposed guidelines for the CBPR proposal writing and peer review (study section) process, perhaps recommendations are needed for improving the quality of reports for CBPR studies. O'Toole, in the *Journal of General Internal Medicine* special issue on CBPR, suggested the need for a "common language" regarding CBPR and describes a potential process for CBPR findings in the health sciences literature; he articulates this approach as "research-plus" that is methodologically rigorous while maintaining important contributions to the relevance and translation of research.[235]

Publication guidelines, like those for proposal review should 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 more research dollars, researchers and community members must hold themselves to the highest possible standards on both sides of this issue.

Support for CBPR from the Community of Scholars

If CBPR is to achieve its full potential as a research process or methodology uniquely designed to address some of the most challenging health care issues of our time, full support is required from the "community of scholars," located in neighborhoods as well as universities. Funding agencies must understand the full benefits and complexities of CBPR to generate RFAs that elicit high-quality proposals incorporating the essential research and participatory elements of this approach. Communities must take the risk to become full partners in the research enterprise, contributing their unique knowledge and experience while safeguarding their interests. Reseachers must combine excellent science with compassionate and respectful community partnerships; journals must create opportunities to highlight and disseminate CBPR research products; and health care providers and policymakers must be guided by the evidence

that results from the collaborative efforts. Enhancing any one component of this cycle is likely to have a positive effect on the others, ultimately strengthening and sustaining community-based participatory research.

Table 10. Indexing CBPR studies: core terms

I. CBPR concept	**II. Research process terms**	**III. Research population terms**
"community based participatory research"	*Health Services Research Research	*Medically Underserved Area
"community based research"	*Process Assessment, Health Care	*Minority Groups
"community driven research"	*Outcome and Process Assessment, Health Care	Ethnic Groups
"CBPR"	*Program Evaluation	*Disabled persons
*Community Health Services	*Data Collection	*Socioeconomic factors;, includes:
*Community-Institutional Relations OR Interinstitutional Relations	*Program Development	Career Mobility
	Health Surveys	Educational Status
	Health Promotion	Employment
*Community Health Planning	Health Behavior	Family Characteristics
*Community Networks	Health Education	Income
*Community Health Centers		Medical Indigency
*Consumer Participation		Occupations
*Public Health		Poverty
Community Health Aides		Social Change
Community Medicine		Social Class
Voluntary Workers		Social Conditions
"lay health advisors" OR LHA		Population; includes:
"coalition building"		Rural, suburban and urban