Community-Based Participatory Research: A Summary of the Evidence

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Preface

The Agency for Healthcare Research and Quality (AHRQ), through its Evidence-Based Practice Centers (EPCs), sponsors the development of evidence reports and technology assessments to assist public- and private-sector organizations in their efforts to improve the quality of health care in the United States. This report on Community-Based Participatory Research: A Summary of the Evidence was requested and funded by the The Agency for Healthcare Research and Quality. Partial funding for the evidence report was provided by the National Cancer Institute, Division of Cancer Control and Population Sciences, and by the National Institute of Health's Office of Behavioral and Social Sciences. The reports and assessments provide organizations with comprehensive, science-based information on common, costly medical conditions and new health care technologies. The EPCs systematically review the relevant scientific literature on topics assigned to them by AHRQ and conduct additional analyses when appropriate prior to developing their reports and assessments.

To bring the broadest range of experts into the development of evidence reports and health technology assessments, AHRQ encourages the EPCs to form partnerships and enter into collaborations with other medical and research organizations. The EPCs work with these partner organizations to ensure that the evidence reports and technology assessments they produce will become building blocks for health care quality improvement projects throughout the Nation. The reports undergo peer review prior to their release.

AHRQ expects that the EPC evidence reports and technology assessments will inform individual health plans, providers, and purchasers as well as the health care system as a whole by providing important information to help improve health care quality.

We welcome written comments on this evidence report. They may be sent to: Director, Center for Outcomes and Evidence, Agency for Healthcare Research and Quality, 540 Gaither Road, Rockville, MD 20850.

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The investigators deeply appreciate the considerable support, commitment, and contributions of the EPC team staff at RTI and UNC. From UNC, we thank the EPC Co-Director, Timothy S. Carey, MD, MPH; Research Assistant Donna Curasi; and abstractors, Karen Pilliod, MPH; Jill McClain, MA; and Laura Sterling, MD. We also express our gratitude to Debra J Bost, editor, and Loraine Monroe, EPC word processing specialist, at RTI International.

We also extend our appreciation to the members of our Technical Expert Advisory Group (TEAG), who provided advice and input during our research process. TEAG members were Jack Geiger, MD; Russell Glasgow, PhD; Barbara Sabol, RN; Deborah Jones-Saumty, PhD; Jesus Ramirez-Valles, MPH, PhD; Gwen Bampfield-Wright, JD, MSW; Glenn White, PhD; Alex Allen, MSA; Meredith Minkler, DrPH; Barbara Israel, DrPH; and Monika Suchowierska, MA, BCBA. We would also like to thank those who did not serve in the capacity as TEAG members, but were Expert Meeting participants: Benjamin Fraticelli, MDiv, MPH; Tom Kelly; Elmer Freeman; Linda Randolph, MD, MPH; Victor Rubin, PhD; Jeam Schensul, PhD; JoAnn Umilani Tsark, MPH; Tony Whitehead, PhD; and Jon Kerner, PhD.

We deeply appreciate the insights of our peer reviewers. The TEAG members who served as peer reviewers include Alex Allen, Gwen Bampfield-Wright, Barbara Israel, Deborah Jones-Saumty, Mereidith Minkler, and Jesus Ramirez-Valles**.** In addition, Ann Beal, MD, Tom Bruce, MD, Paul Estabrooks, PhD, Victor Rubin, PhD, Sarena Seifer, MD, Shobha Srinivasan, Ph.D., JoAnn Umilani Tsark, MPH, and Tony Whitehead, PhD.

Structured Abstract

Context: Community-based participatory research (CBPR) is a collaborative approach to research that combines methods of inquiry with community capacity-building strategies to bridge the gap between knowledge produced through research and what is practiced in communities to improve health. Interest is growing rapidly for academic institutions, health agencies, and communities to form research partnerships; few agreed-upon guidelines describe how to develop or evaluate CBPR proposals or what resources are required to promote successful collaborative research efforts.

Objectives: This systematic review consolidates literature on health-related CBPR. We addressed the following key questions:

Key Question 1: What defines CBPR?
Key Question 2: How has CBPR been implemented to date with regard to the quality of research methodology and community involvement?
Key Question 3: What is the evidence that CBPR efforts have resulted in the intended outcomes?
Key Question 4: What criteria and processes should be used for review of CBPR in grant proposals?

Data Sources: For KQ 1-4, we searched standard electronic databases (MEDLINE®, Cochrane Collaboration resources, Psycinfo, and Sociofile) for all years using specified Medical Subject Headings terms. We identified a forthcoming special journal issue and hand-searched reference lists of relevant articles. For KQ 4, we also reviewed websites for funding agencies and talked with federal agency staff.

Study Selection: For KQ 1, we used peer-reviewed articles that synthesized the evolution of, values for, or lessons learned from collaborative research. For KQ 2 and 3, we included peer-reviewed CBPR studies published in the English language, conducted in the United States and Canada, and with at least one community collaborator.

Data Extraction: To review articles for KQ 1 through 3, we created separate abstraction forms. We entered abstracted data for KQ 1 into a domain matrix and for KQ 2 and 3 into evidence tables. We created quality rating forms to assess each study's research methods and adherence to CBPR principles of community collaboration.

Data Synthesis: We reviewed a total of 185 articles: 55 for KQ1; 123 for KQ 2 and 3; and 7 for KQ 4. The 123 articles for KQ 2 and 3 pertain to 60 CBPR studies. Of the 30 intervention studies, 12 had been completed and evaluated. Quality ratings for these suggested stronger research scores for the experimental studies than for the others, although nonexperimental studies also showed modest effects on health outcomes. Quality ratings for community participation were strongest for recruitment/retention and intervention design followed by development and pilot testing of measures. Steering committees or advisory boards were the

main mechanisms for sharing research decisionmaking, but these formal structures generally did not develop research questions or proposals.

The number of high-quality CBPR publications has increased recently, which may reflect more targeted funding and special journal issues on this theme. Guidelines are still needed to assist funding agencies and grant applicants and reviewers in achieving the best balance of rigorous research and optimal collaboration among communities and institutions.

Conclusions: Many CBPR studies had strong community-institution collaborations; relatively few combined this type of collaboration with solid research methods. Our synthesis of this literature enabled us to produce guidelines to improve the quality of and funding for CBPR.

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Evidence Report

Chapter 1. Introduction

Background

Community-based participatory research (CBPR), as an approach to enhance both research and community outcomes, has received increased attention as the academic and public health communities struggle to address the persistent problem of disparities in the use of health care and health outcomes for several populations, including those identified by diagnosis, socioeconomic status, lack of health insurance, and membership in various racial and ethnic groups.[1-6] Few guidelines exist to indicate how research proposals should be evaluated and what resources are required to promote successful efforts. 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 growing impatient with the gap between knowledge produced through conventional research and translation of this research into interventions and policies to improve the health of immigrants and communities of color.[7] [2,8-12]

For public health practitioners, the challenge of sustainable behavior change is compounded by long-standing social and historical conditions of inequality embedded in the very fabric of society.[10] For researchers, this broad range of external forces jeopardizes the stability of observations. Consequently, concepts such as external comparisons and generalization to some idealized population, as used in inferential statistics, may make only limited sense.[13] For immigrants and communities of color, historic mistrust of the health care system and research compromises the ability of researchers and health practitioners to identify and address their health needs.[14-16]

Given these challenges, the significance of an approach that builds the capacity of *communities to function as co-investigators* with health agencies and academic institutions before, during, and after the research process has re-emerged. The assumption is that such an approach will engender greater commitment among all research partners to uncovering social and behavioral determinants of health and to developing innovative, long-term interventions. As yet, no clear consensus exists in public health and health services research to answer the question, "What constitutes a community?" "Whose participation is to be solicited and incorporated?" and "What evidence is needed for whom on 'best practices' of community-based participatory research?" Also needed are mechanisms for research evaluation and funding that promote optimal collaboration among communities, health agencies, and academic institutions for identifying and modifying research priorities within populations disenfranchised from the political and health policymaking process.

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

Community-Based Participatory Research: Defining the Approach

CBPR has been proposed as an approach that combines research methods and community capacity-building strategies to bridge the gap between knowledge produced through research and translation of this research into interventions and policies.[2,7,9-12,17-20]

CBPR's distinction from other community-based research approaches, which view "community" as a setting or location, is the recognition of community as a social entity with a sense of identity and shared fate. Working *with* rather than *in* communities, CBPR attempts to strengthen a community's problem-solving capacity through collective engagement in the research process. The seminal review of community-based research literature by Israel and colleagues[11] defines CBPR as "[a] collaborative approach to research that equitably involves, for example, community members, organizational representatives, and researchers in all aspects of the research process. The partners contribute unique strengths and shared responsibilities to enhance understanding of a given phenomenon and the social and cultural dynamics of the community, and integrate the knowledge gained with action to improve the health and well-being of community members (p. 177)."

In their review of participatory research studies,[21-23] Green and colleagues offer the following definition:[23] "Participatory research is systematic inquiry, with the collaboration of those affected by the issue being studied, for purposes of education and taking action or effecting social change" (p. 194). Using their own findings, this Canadian group developed a set of criteria for evaluating research proposals[23] that we have adapted and propose to refine further to apply to articles in our evidence tables. Green and colleagues defined community[23] as "any group of individuals sharing a given interest; this definition includes cultural, social, political, health, and economic issues that may link together individuals who may or may not share a particular geographic association. This definition also includes the traditional concept of community as a geographic entity" (p. 186). Although many researchers and practitioners offer definitions and descriptions of community and CBPR, no clear consensus has emerged to move the field forward during a time when interest is growing rapidly.[24-30]

Nevertheless, common themes are that the CBPR approach (a) recognizes the importance of social, political, cultural, and economic systems to health behaviors and outcomes; (b) engages community members in choosing research topics, developing projects, collecting data, and interpreting results; (c) emphasizes both qualitative and quantitative research methods; and (d) puts high priority on translation of the findings of basic, intervention, and applied research into changes in practice and policy. More difficult to prescribe, however, is the degree to which each of these criteria must be fulfilled to satisfy the elements of CBPR.

Community-Based Participatory Research: Clarifying the Benefits

Done properly, CBPR should benefit community participants, practitioners, and researchers alike. CBPR creates bridges between scientists and communities allowing both to gain in knowledge and experience.[31-35] This collaboration assists in developing culturally appropriate measurement instruments, thus making projects more effective and efficient.[36,37] Finally, CBPR establishes a level of trust that enhances both the quantity and the quality of data collected.[31,38-40]

The ultimate benefit is the prospect of examining the community's own unique circumstances to test and adapt best practices to its own needs.[2,31,33,36,41-47]

Production of This Evidence Report

Background

In November 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."[48] 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 is to be used 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."[48] Among the recommendations was a request that an AHRQ Evidence-based Practice Center (EPC) synthesize evidence on the conduct and evaluation of CBPR. A national group could then use such a review as the basis for CBPR guidelines with the following anticipated benefits: enhanced stature for CBPR; guidance to potential partners entering into CBPR projects; and improved assessment criteria and mechanism for funders to review CBPR proposals.

AHRQ awarded this evidence report to the RTI International–University of North Carolina Evidence-based Practice Center (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 the following key questions:

- What defines community-based participatory research?
- How has CBPR been implemented to date with regard to the quality of research methodology and community involvement?
- What is the evidence that CBPR efforts have resulted in intended outcomes?
- What criteria and processes should be used for review of CBPR in grant proposals?

Users of This Evidence Report

The RTI-UNC EPC team anticipates that its report and subsequent publications will assist several audiences. Community leaders interested in initiating research projects will find guidance on expectations of what a true collaboration might look like, including their obligations

as research partners. Public health and health services researchers and practitioners new to CBPR will gain insights into their obligations as partners with communities in research. Funders in both federal and foundation arenas will find criteria that they can use to evaluate CBPR proposals.

Organization of This Evidence Report

Chapter 2 describes our methods, including key questions and analytic framework, our search strategies and inclusion/exclusion criteria, and our approach to grading the quality of articles and rating the strength of evidence. In Chapter 3, we present the results of our literature search and synthesis of retained articles. Chapter 4 further discusses the findings and offers our recommendations for future research. Our references and included studies and a listing of excluded studies follow Chapter 4. Appendixes include a detailed description of our search strings (Appendix A), an example of our quality assessment form (Appendix B), detailed evidence tables (Appendix C), and peer reviewers (Appendix D). Appendixes and Evidence Tables cited in this report are provided electronically at http://www.ahrq.gov/clinic/epcindex.htm.

Chapter 2. Methods

In this chapter, we document the procedures that the RTI International–University of North Carolina Evidence-based Practice Center (RTI-UNC EPC) used to develop this comprehensive evidence report on community-based participatory research (CBPR). To set the framework for the review, we first discuss our analytic framework and then briefly describe the preliminary expert meeting and our Technical Expert Advisory Group (TEAG) and their suggested changes to the analytic framework and key questions. We describe our strategy for identifying articles relevant to our key questions, our inclusion/exclusion criteria, and the process we used to abstract relevant information from the eligible articles and generate our evidence tables. We also discuss our criteria for grading the quality of individual articles and the strength of the evidence as a whole. Finally, we present our approach to collecting information about CBPR funding and explain the peer review process.

Analytic Framework

CBPR is a research approach that can be applied to a variety of study designs addressing a wide range of health outcomes. For that reason alone, no one diagram can illustrate all possible causal pathways. Thus, our analytic framework (depicted in Figure 1) documents the primary elements of most studies (study design, measurement, intervention, data analysis); the traditional research approaches associated with these elements; and what is added to this mix through the use of CBPR. We also note the hypothesized benefits of CBPR to the research process.

Table 1 elaborates potential benefits of CBPR to the community and some of the research challenges associated with CBPR. The analytic framework and table reflect the most comprehensive picture of CBPR developed to date, including identifying the health concern, developing a measurement system, and testing an intervention, but, as expected, only a limited number of empirical studies tend to include all these elements.

Preliminary Expert Meeting

In November 2002, the RTI-UNC EPC convened a group of experts including some members of our TEAG (see Appendix D) to provide early guidance on our work. This group discussed key issues and audiences for the CBPR report; defined clear and appropriate research questions and set some priorities on those questions, so that we could target our literature search; and helped to identify appropriate databases and other resources for this systematic review. In particular, we presented draft key questions to the expert meeting attendees. Based on their feedback and on additional comments from our TEAG in later conversations, we revised these questions further to create the set that guided the remainder of our work.

We presented the analytic framework at our expert meeting. In reviewing the framework, the meeting attendees listed several common elements of CBPR, participatory action research

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(PAR), action research (AR), or participatory research (PR) that they advised us to take into account. These common elements included

- jointly identifying research priorities with the community,
- a higher level of involvement from both the researcher and the community,
- promoting social change,
- guiding partnerships across sites,
- co-education/co-learning across researchers and communities,
- community health indicators,
- generating instrumental and practical knowledge,
- an increased focus on process, and
- power-sharing between the researcher and the community.

Adding to the complexity of our work was the fact that our preliminary searches had suggested that community-based and participatory approaches to research might not be classified as CBPR. Expert panel members (including our TEAG) shared our concern about the extent to which key terms are inconsistently assigned to articles when they are indexed in commonly used databases. They listed several terms apart from CBPR, participatory action research, action research, or participatory research that imply involvement in the community. These terms include action science, collaborative inquiry, partnership research, and empowerment evaluation.

We also employed the expertise of the TEAG throughout the process. A brief description of the TEAG is presented below.

Role of the Technical Expert Advisory Group

The TEAG represented 11 CBPR experts who provided assistance throughout the project. The TEAG members brought diverse perspectives to this review from their work as community research partners, and academic researchers. As in all such systematic reviews, the TEAG was expected to contribute to AHRQ's broader goals of (1) creating and maintaining science partnerships as well as public-private partnerships and (2) meeting the needs of an array of potential customers and users of its products. Thus, the TEAG was both an additional resource and a sounding board during the project.

To ensure robust, scientifically relevant work, we called on the TEAG to react to work in progress and advise us on substantive issues or possibly overlooked areas of research. TEAG members participated in conference calls and discussions through e-mail to

- refine the analytic framework and key questions at the beginning of the project;
- discuss the preliminary assessment of the literature, including inclusion/exclusion criteria; and
- provide input on the information and categories included in evidence tables.

Because of their extensive knowledge of this topic and their active involvement in CBPR, we also asked TEAG members to participate in the external peer review of the draft report.

Key Questions

Using these inputs, we arrived at a final set of key questions, presented below, to guide the literature searches and synthesis. Table 2 presents the four key questions (KQ 1 through 4) along with their subparts.

KQ 1. What defines CBPR?

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?

Literature Search Strategy

Inclusion and Exclusion Criteria

Based on the final key questions specified following the expert meeting and further discussions with our TEAG, we generated a list of inclusion and exclusion criteria for each key question. Generally, we included human studies; all ages and both sexes, English language only; and studies done in the United States and Canada (English-speaking North America). We included a broader set of international studies for purposes of describing the history and definition of CBPR, but systematically reviewing empirical studies conducted in vastly different sociocultural and political climates would have far exceeded the scope of this effort.

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 information to be abstractable. We identified several manuscripts that were limited to descriptions of CBPR processes and partnership development that did not include sufficient information on projects or outcomes; we also excluded these studies from our review.

On the advice of our TEAG and based on our cumulative definition of CBPR, we elected to limit our review to studies that defined community at the level of study participants; thus, we excluded studies that used participatory techniques to involve health professionals in the research process. For example, an extensive body of research in the literature addresses participatory action research as a method to include and empower nurse professionals in continuing education and career development.[49,50] Likewise, many studies involve physicians and other health care professionals in the process of identifying barriers to health care delivery and testing intervention approaches to address these barriers.[51,52] Although these types of investigations represent an important approach to involving those who can both improve the research process and enhance

the potential for implementing findings, we elected to narrow our review to participatory research involving primarily community members, worksite employees, and other individuals not involved with the health care delivery process.

We did not restrict the search by date of publication. The last of our systematic searches was conducted on March 3, 2003. After that date, we continued to search for citations that were necessary to provide a complete overview of studies that we had already identified through our systematic searches and TEAG suggestions. We performed these latter searches on individual author names or study names (or both), mainly during the process of data abstraction. We were also able to obtain advance copies of articles to be published in a special issue of the *Journal of General Internal Medicine* focusing on CBPR, which appeared in July 2003.

Relevant Data Sources

For KQ 1, 2, and 3, we used three strategies to include all the current valid research related to the key questions: systematic searches based on search terms and author names, consultation with the TEAG, and hand searches of reference lists. First, we searched standard electronic databases such as MEDLINE®, Cochrane Collaboration resources, PsycInfo, and Sociofile using specified search terms. Based on the inclusion/exclusion criteria above and the additional key terms identified by our expert meeting attendees, we generated a list of Medical Subject Heading (MeSH) search terms (Table 3). The TEAG reviewed these terms to ensure that we were not missing any critical areas and suggested additional searches on specific authors and studies. We included these names in our systematic search strategy below. This list represents our collective decisions on the MeSH terms to use for all searches.

Second, we consulted with the TEAG about any studies that were under way but not yet published. Key among the sources of information identified through the TEAG was the special CBPR issue of the *Journal of General Internal Medicine* (July 2003). This publication date was relatively late in our abstraction process, so we were concerned that we would miss this important source of literature. Fortunately, we were able to obtain and abstract data from these journal articles before they were published.

Third, we conducted hand searches of the reference lists of relevant articles to ensure that we did not miss any relevant studies that we had not identified through our MeSH terms. 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.

Because CBPR work requires long-term and deliberate collaborations before, during, and perhaps after a research project, this process often results in numerous articles through which the investigators describe their methods and results. This phenomenon is exacerbated by journal limitations on length of submissions, which tends to promote fragmentation of the work into multiple articles. Our original search terms often did not capture these additional citations because the authors do not specifically use CBPR or related terminology in describing their efforts. Moreover, in some cases, we determined that we missed relevant (sets of) articles because they simply had never been categorized or indexed as relating to CBPR at all, evidently because the investigators did not refer to their CBPR methodology. We were able to identify

them only from *review* articles relating to CBPR. The review articles were especially important because they often included extensive, completed, often well-funded projects that covered a wide array of CBPR elements of the type we needed to examine in this evidence report (e.g., those of the Urban Research Centers).

For KQ 4, we compiled any peer-reviewed publications that could contribute to the research questions. Very few articles directly addressed CBPR funding issues *per se*;[53] rather, the materials we found tended to describe funding mechanisms for CBPR, such as Urban Research Centers funded by the Centers for Disease Control and Prevention (CDC)[54-58] and the Environmental Justice funding mechanism of the National Institute of Environmental Health Sciences (NIEHS).[59] We also reviewed the Web sites for several funding agencies supporting CBPR, talked with federal staff involved with the Interagency Working Group for Community-Based Participatory Research,[60] and interviewed individuals at the CDC and National Institutes of Health (NIH) who were involved with developing CBPR Requests for Applications (RFAs) and the grant review process more generally.

Literature Search Results

Across the four key questions, we identified a total of 650 abstracts for review through our systematic searches. We identified an additional 599 abstracts by using names and search phrases suggested by our expert meeting attendees and TEAG. While reviewing these abstracts, we identified 159 additional citations through hand searches that we considered necessary to decide whether the study qualified for inclusion in our review. Finally, we retained and pulled 297 articles for complete review and excluded 112 studies.

A common reason for exclusion was that the study was a review article listing several CBPR studies, with insufficient information on any individual study to be included in an evidence table. Another frequent reason for exclusion was that, on review, the study did not have sufficient elements of community involvement and/or research to be considered CBPR. Other reasons for exclusion included lack of relevance to the topic (for instance, not health related), or unabstractable information (as with process evaluations that focus on participatory processes with no details on research collaborations) (see list of excluded articles, page 111).

Ultimately, we retained 55 articles for KQ 1; we were unable to obtain three identified articles through interlibrary loan requests or Web searches. For KQ 2 and 3, we identified 123 articles that constituted 60 studies. For KQ 4, we used 7 articles to inform the results and discussion.

Of the 123 articles identified for KQ 2 and 3, a sizable proportion (55 articles or 45%) were identified through hand searches. A key limitation of employing secondary and tertiary sources to identify CBPR studies is that these studies are often not self-identified as CBPR. Although a separate review article may have mentioned elements of their participatory approach, the authors may not have intended to conduct a full-fledged CBPR study. For these studies, evaluation against elements of a CBPR scale is perhaps unfair and creates unnecessary inconsistencies among the pool of included studies.

Therefore, we chose to limit our reliance on hand searches by considering citations relevant only to the intervention mentioned in the article originally obtained through our systematic searches. For instance, in the case of the Health is Gold! study, several other interventions had been conducted as well, but we chose to limit review of these citations to the intervention identified in the July 2003 issue of the *Journal of General Internal Medicine*. Using this strategy prevented an exponential expansion in our scope of work while still allowing us to capture a larger pool of studies; in addition, it brought some degree of consistency to the studies included in the final analysis in that all the studies were identified by CBPR or related key words. As a consequence of this strategy, however, we cannot claim this review to be exhaustive.

An additional limitation of this review is that it necessarily depends on results having been reported in peer-reviewed publications. Articles that focus on process evaluation may not provide any details on study design and methodology. Conversely, articles focusing on study outcomes may choose either not to report the CBPR process or to report it only partially, depending on the focus of the journal article and limitations on length. An additional factor is that no clearly established standards for reporting CBPR elements exist. Given the great variability of reporting, we are able to provide only information on whether these elements were reported; their absence cannot be taken as proof that the study did not incorporate these elements. By the same token, the relative absence of negative findings in this report is likely to be attributable to a form of publication bias, in which unsuccessful collaborations are rarely reported.

Data Collection and Assessment

KQ 1 through 3 differ from KQ 4 in several ways, including the underlying conceptual issues and the purposes to which the eventual searches and syntheses will be put. For that reason, we discuss some aspects of our methods separately for KQ 1 through 3 and for KQ 4.

For KQ 1, 2, and 3, the data collection process involved abstracting relevant information from the eligible articles and generating summary evidence tables that present the key details and findings for the articles. Trained abstractors were paired with the Study Director, Meera Viswanathan, PhD, or with one of the Co-Scientific Investigators, Eugenia Eng, DrPH, or Alice Ammerman, PhD, RD, or with Carmen Samuel-Hodge, PhD, MPH, RD.

Designing Abstraction Procedures

We employed our analytic framework and feedback from the expert meeting and TEAG to guide development of our abstraction tables (see Appendix B), which we designed to approximate the final evidence tables as closely as possible. We also used the framework and feedback to guide the quality rating system (described below). We divided both the abstraction tables and quality ratings into primary research and primary community-based participatory elements. In this way, we were able to describe the studies more fully and evaluate the research and community participation elements separately rather than forcing community participation elements into research methodology categories.

For KQ 2 and 3, because of the multiplicity of articles from a single study, the first step in data collection required grouping articles by study. The Study Director reviewed all articles marked for inclusion and grouped them by study and then sent all articles relating to a single study to our abstractors. Abstractors sometimes identified additional articles necessary to complete the evidence table, and they also recommended articles for exclusion. The abstracts also determined whether the group of articles related to multiple interventions (listed under the same study name) and, if so, forwarded queries to the senior reviewer to select the relevant intervention for abstraction. Once we had compiled a complete set of articles pertaining to a single study, the abstractors keyed the data into an evidence table. The senior reviewer paired with the abstractor performed quality control assessments by reviewing each of the evidence tables against the original articles and making revisions where needed.

Training Abstractors

All abstractors attended two training sessions. At the first session, we explained the process and goals of data abstraction; we then sent the abstractors home with an article to review. We reconvened the group and, through a review of the test article, ensured that the abstractors understood what was expected of them. At that time, we determined that the abstractors were able to abstract the data as required and began the data abstraction process. The Research Coordinator monitored progress and routed the data abstractors' questions or issues to the Study or Co-Scientific Directors.

Developing Data Abstraction Forms

For KQ 1, one of the Scientific Directors (EE) took sole responsibility for generating a data abstraction form, and it formed the basis for the respective evidence table. For KQ 2 and 3, the Study Director (MV) and the Co-Scientific Directors (EE, AA) together created a single form that served as a data abstraction form as well as the template for the respective evidence tables. We revised and refined the form through multiple rounds of pretesting on different articles spanning the entire range of interventions to ensure that it would adequately capture all relevant issues. We solicited feedback from the data abstractors during training to refine further these various forms.

Developing Evidence Tables and Preparing the Draft Evidence Report

The two final evidence tables are found in their entirety in Appendix C. The first covers evaluated interventions and the second interventions either not completed or not evaluated. Entries are sorted by study design and then listed alphabetically by their study names. When articles gave no "official" study names, we used the key focus of the study. Entries in the evidence table may combine information from multiple articles to provide more complete information on a given study. A list of abbreviations used in the tables appears at the beginning of the appendix.

Grading the Quality of Individual Articles and Rating the Strength of Evidence

We also developed forms to guide our evaluations of the quality of individual articles in this literature and the degree to which investigators had implemented CBPR principles in their research. Specifically, we developed two quality rating forms: one related to research quality that drew on previous work of the RTI-UNC EPC[61,62] and the other rated the quality of collaboration with a community.

CBPR reflects significant diversity in outcomes, research methodology, and measures. Thus, we elected to grade the quality of only two types of studies (often represented by a set of published articles): (1) those that represented a completed intervention study and (2) those that represented an observational study that was not limited to a baseline needs assessment but rather was designed to allow extrapolation to a broader population. While this limits the scope of the research graded for quality, it allows application of a consistent set of research criteria.

We tested several drafts of our quality grading instruments and revised them numerous times to assure that they captured the desired information. The final grading forms can be found in Appendix B. Research elements of intervention studies were grouped into the following nine categories: (1) the research question, (2) study population and external validity, (3) control/comparison group, (4) intervention, (5) internal validity and intervention fidelity, (6) primary outcome measures, (7) statistical analysis, (8) blinding, and (9) funding source. CBPR elements rated included the following 10 dimensions: (1) selection of research question, (2) proposal development, (3) financial responsibility for grant funds, (4) study design, (5) recruitment and retention, (6) measurement instruments and data collection, (7) intervention development, implementation, (8) interpretation of findings, (9) dissemination of findings, and (10) application of findings to health concern identified.

One key element of quality grading involves whether the articles or investigators at least disclosed their funding sources, because of the potential for bias associated with the funding source, whether private or public.[62] (An example might be funding from the Dairy Council for a CBPR study promoting milk consumption.) We did not directly include information about funding source in our quality grading scheme, because of the dissimilarity between this element (on the one hand) and items drawn from epidemiology or validated methods research (on the other). In the final evidence report, evidence tables record either the actual funding source or the fact that the investigators did not supply the information in their published articles.

Two senior investigators completed study quality assessments by rating the studies separately, comparing scores, and discussing any discrepancies until they resolved them and assigned a single score. We assigned a score of "1i" for insufficient information, "1p" for poor, "2" for fair, and "3" for good.

External Peer Review

As is customary for all evidence reports and systematic reviews done for AHRQ, the RTI-UNC EPC requested review of this report from a wide array of outside experts in the field and from relevant professional societies and public organizations. AHRQ also requested review from its own staff and appropriate federal agencies. We received 13 reviews and revised this final report, as appropriate, on the basis of this feedback.

Figure 1. Analytic framework for community-based participatory research

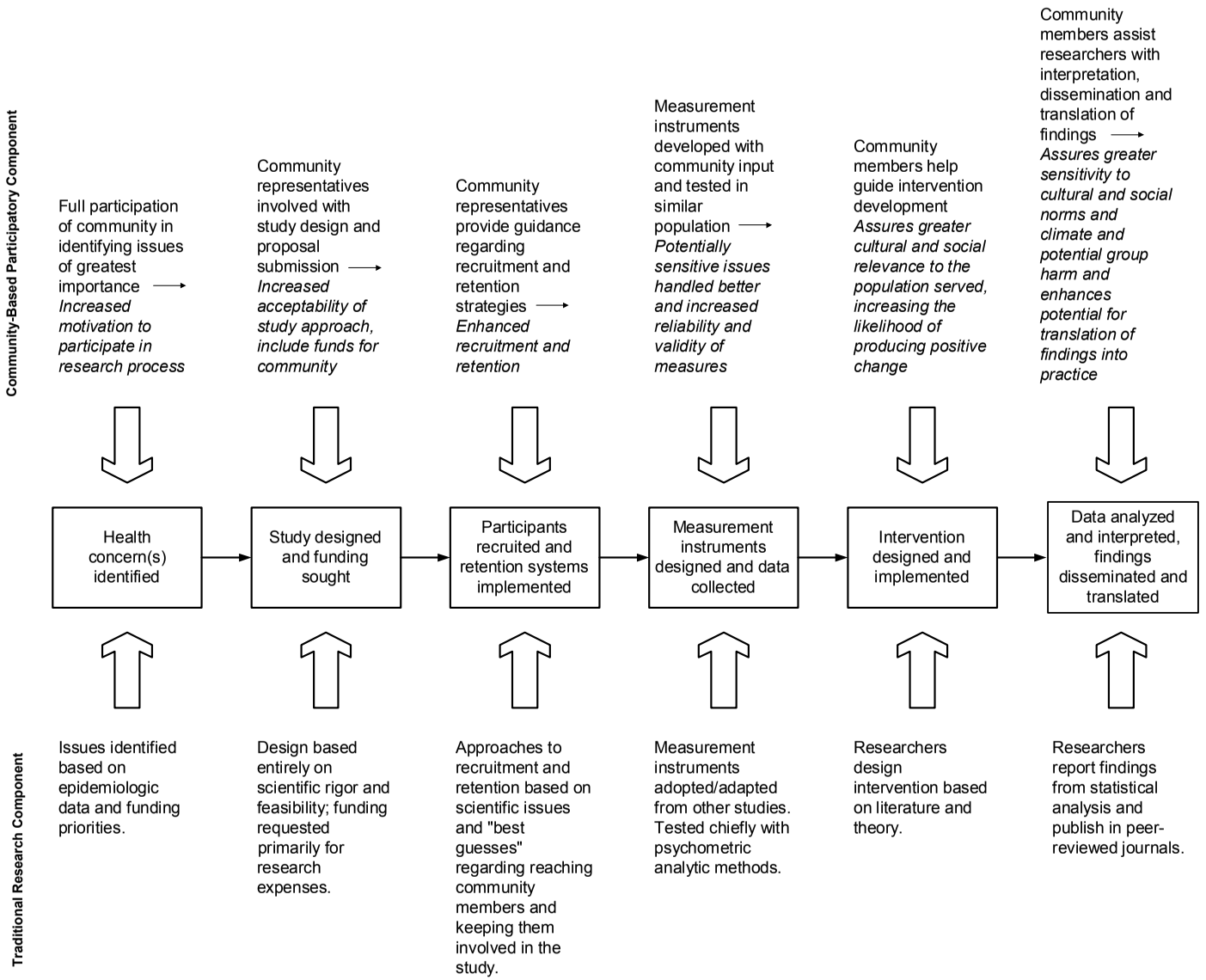

Table 1. Critical elements in community-based participatory research

CBPR Implementation and Potential Impact				
Research Element	**CBPR Application**	**Community Benefits**	**Research Benefits**	**Research Challenges**
Assembling a research team of collaborators with the potential for forming a research partnership	Identifying collaborators who are decisionmakers that can move the research project forward	Resources can be used more efficiently	Increases the probability of completing the research project as intended	Time to identify the right collaborators and convincing them that they play an important role in the research project
A structure for collaboration to guide decisionmaking	Consensus on ethics and operating principles for the research partnership to follow, including protection of study participants	The beginning of building trust and the likelihood that procedures governing protection of study participants will be understood and acceptable	An opportunity to understand each collaborator's agenda, which may enhance recruitment and retention of study participants	An ongoing process throughout the life of research partnerships that requires skills in group facilitation, building consensus, and conflict accommodation
Defining the research question	Full participation of community in identifying issues of greatest importance; focus on community strengths as well as problems	Problems addressed are highly relevant to the study participants and other community members	Increased investment and commitment to the research process by participants	Time consuming; community may identify issues that differ from those identified by standard assessment procedures or for which funding is available
Grant proposal and funding	Community leaders/members involved as a part of the proposal writing process	Proposal is more likely to address issues of concern in a manner acceptable to community residents	Funding likelihood increases if community participation results in tangible indicators of support for recruitment and retention efforts, such as writing letters of support, serving on steering committee or as fiscal agents or co-investigators	Seeking input from the community may slow the process and complicate the proposal development effort when time constraints are often present
Research design	Researchers communicate the need for specific study design approaches and work with community to design more acceptable approaches, such as a delayed intervention for the control group	Participants feel as if they are contributing to the advancement of knowledge vs. as if they are passive research "subjects," and that a genuine benefit will be gained by their community	Community is less resentful of research process and more likely to participate	Design may be more expensive and/or take longer to implement Possible threats to scientific rigor

Table 1. Critical elements in community-based participatory research (continued)

CBPR Implementation and Potential Impact				
Research Element	**CBPR Application**	**Community Benefits**	**Research Benefits**	**Research Challenges**
Participant recruitment and retention	Community representatives guide researchers to the most effective way to reach the intended study participants and keep them involved in the study	Those who may benefit most from the research are identified and recruited in dignified manner rather than made to feel like research subjects	Facilitated participant recruitment and retention, which are among the major challenges in health research	Recruitment and retention approaches may be more complex, expensive, or time consuming
Formative data collection	Community members provide input to intervention design, barriers to recruitment and retention, etc. via focus groups, structured interviews, narratives, or other qualitative method	Interventions and research approach are likely to be more acceptable to participants and thus of greater benefit to them and the broader population	Service-based and community-based interventions are likely to be more effective than if they are designed without prior formative data collection	Findings may indicate needed changes to proposed study design, intervention, and timeline, which may delay progress
Measures, instrument design and data collection	Community representatives involved in extensive cognitive response and pilot testing of measurement instruments before beginning formal research	Measurement instruments less likely to be offensive or confusing to participants	Quality of data is likely to be superior in terms of reliability and validity	Time consuming; possible threats to scientific rigor
Intervention design and implementation	Community representatives involved with selecting the most appropriate intervention approach, given cultural and social factors and strengths of the community	Participants feel the intervention is designed for their needs and offers benefits while avoiding insult; provides resources for communities involved	Intervention design is more likely to be appropriate for the study population, thus increasing the likelihood of a positive study	Time consuming; hiring local staff; may be less efficient than using study staff hired for the project
Data analysis and interpretation	Community members involved regarding their interpretation of the findings within the local social and cultural context	Community members who hear the results of the study are more likely to feel that the conclusions are accurate and sensitive	Researchers are less likely to be criticized for limited insight or cultural insensitivity	Interpretations of data by non-scientists may differ from those of scientists, calling for thoughtful negotiation
Manuscript preparation and research translation	Community members are included as coauthors of the manuscripts, presentations, newspaper articles, etc., following previously agreed-upon guidelines	Pride in accomplishment, experience with scientific writing, and potential for career advancement; findings are more likely to reach the larger community and increase potential for implementing or sustaining recommendations	The manuscript is more likely to reflect an accurate picture of the community environment of the study	Time consuming; requires extra mutual learning and negotiation

Table 2. Key questions for the evidence report on community-based participatory research

1. What defines CBPR?
   - 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?

2. How has CBPR been implemented to date with regard to the quality of research methodology and community involvement?
   - What is the quality of research methodology?
     - Study design
     - Measurement
     - Data collection
     - Analysis
   - What is the level of community involvement in the research process?
     - Priority setting and hypothesis generation
     - Methods selection
     - Proposal development and funding
     - Study design and implementation, data collection tools, recruitment and retention, analysis and interpretation
     - Intervention design and implementation
     - Translation and dissemination of research findings
     - Integration and sustainability

3. What is the evidence that CBPR efforts have resulted in the intended outcomes?
   - Improved research quality outcomes
   - Community capacity outcomes
   - Health (broadly defined) outcomes

4. What criteria and processes should be used for review of CBPR in grant proposals?
   - What criteria should high-quality grant applications meet?
   - What guidance can be offered to funding organizations and applicants?
   - Who should be involved in the review process? What should be the role of the community?
   - What are current approaches by funders to soliciting and reviewing CBPR grant proposals?

Table 3. Key databases and search terms

Databases	Search Terms	Limits
MEDLINE	Community-based participatory research or CBPR or participatory research or action research or participatory action research or participatory evaluation or community driven research or action science or collaborative inquiry or empowerment evaluation; expert names (TEAG members and expert meeting attendees)	English language
Cochrane	Community-based participatory research; community + action + research; empowerment evaluation; collaborative inquiry	None
Sociofile	Community-based participatory research or CBPR or ((action research) and (community or empowerment or participation) and (health or medical or medicine))	None
PsycInfo	Community-based participatory research or CBPR or ((community based participatory) or (community driven or collaborative inquiry)) and (research)	None

Chapter 3. Results

This chapter presents the results of systematic review of the literature on community-based participatory research (CBPR) conducted by the RTI International–University of North Carolina Evidence-based Practice Center (RTI-UNC EPC) on behalf of the Agency for Healthcare Research and Quality (AHRQ). It presents findings for the four key questions (KQ) introduced in Chapter 2 (Table 2). Briefly, KQ 1 concerned the definitions of the entire field and our quest to develop a synthetic definition that would then provide an appropriate backdrop for the remaining analyses. KQ 2 and 3 focused on (a) how CBPR has been implemented to date, focusing in particular on the quality of research methodology and the level of community involvement in the research process, and (b) what evidence exists that CBPR efforts have resulted in the intended outcomes. KQ 4 dealt with developing criteria for CBPR funding.

We report our results in two main sections of this chapter. First, we describe our analytic strategy; then, we present our results by the four key questions. Tables for this text appear at the end of this chapter. Detailed evidence tables appear in Appendix C.

Analysis Strategy

In developing an approach for synthesizing the literature about CBPR, our review of the literature and conversations with the expert meeting attendees and our Technical Expert Advisory Group (TEAG), as described in Chapter 2, made apparent that each key question would require a different analysis strategy. These are described briefly below.

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 identified 58 peer-reviewed articles that were conceptual in orientation; that is, they synthesized the evolution of, values for, or lessons learned from collaborative research. All articles used CBPR or similar terms, such as action research, collaborative community action research, community-centered praxis, participatory action research, participatory evaluation, and participatory research. Of these 58, we were able to retrieve and review 55 articles; three were not retrievable through interlibrary loan requests or Web site searches by the time we prepared this report. Our review of the abstracts of these three articles suggests that their acquisition would not materially change our results. The articles came from the fields of anthropology,

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

community development, community psychology, disability research, environmental health, health education, health sociology, injury research, mental health, nursing, organization development, patient care, and reproductive health.

We used three reviewers to abstract content from these 55 articles, using a matrix of 28 cells, representing specific CBPR domains in which to enter abstracted verbatim text. The matrix appears in Appendix B. The 28 domains were named as essential elements of participation; essential elements of research; best practices; and expected outcomes for seven components of research (identification of issues and concerns; study design and funding; participant recruitment and retention; measures and data collection; intervention design and implementation; data analysis, interpretation, and dissemination; and partnership structure). One of the Scientific Co-Directors (EE) reread the 55 articles to verify the verbatim text entered onto each cell of the matrix, read through the text entered for each domain, and then summarized the meaning of abstracted text as themes.

KQ 2 and 3: Intervention Studies and Outcomes

As expected, we found a striking degree of variability in the study designs, substantive concerns, and scope of community involvement of CBPR studies. The extent to which these elements were reported in the published literature varied appreciably as well. We looked to the key questions to help us organize this assortment of studies and to decide whether the CBPR studies had achieved their intended outcomes. Specifically, we considered (a) whether the study had an explicitly intended outcome resulting from a planned intervention and (b) whether the outcome was evaluated in sufficient detail in the published literature available to us.

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. Our overriding principle was consistency; we used a definition of interventions that would have a similar meaning across different studies. As an example, although some studies using a participatory action research approach viewed participation in the study as the intervention or the means to achieve their goal of empowerment, we did not classify these studies as having an intervention. We did not restrict interventions to those involving the research community; we included evaluations of studies in which the intervention occurred before researchers became extensively involved in the process. In addressing the evaluation of the intervention, we considered whether the intervention was reported as completed and whether it had been evaluated in a manner that allowed us to make conclusions about whether the intended outcomes had been achieved.

Of the 60 studies relevant to KQ 2 and 3, 30 studies listed interventions and 30 were noninterventional studies (see Table 4 for a list of study names, abbreviations and citations, Table 5 for a summary of characteristics). Evidence Table 1 (Appendix C) comprises 12 of the 30 interventional studies that reported the intervention as complete and evaluated it in a manner that allowed us to assess whether intended outcomes had been achieved. In judging an intervention to be complete (as opposed to ongoing), we considered only whether the intervention had been evaluated; we did not consider whether the intervention was implemented to a lesser degree or in a manner that was different than the intention. Evidence Table 2

(Appendix C) consists of the remaining 18 interventional studies that reported an ongoing intervention (for which we could not find any later citations through our additional searches) and studies with completed interventions that were not fully evaluated (Table 6 presents summary results).

We did not attempt to create an evidence table for the 30 studies that had no interventions. CBPR studies may often focus on basic research questions, initially, without an intervention but with a commitment to disseminating and translating results into interventions and policy. While there is much to be learned about the CBPR approach from these studies, the 30 studies without interventions varied in the extent to which information was abstractable; we present summary information in Table 7.

KQ 4: Funding Criteria for Community-Based Participatory Research

Based on our discussions with the TEAG and AHRQ, we understood our task for KQ 4 to be primarily one of synthesizing our findings from the evidence review for the purpose of guiding future applications (proposal writers), reviewers, and agencies toward submitting and funding the best possible CBPR. To this end, we used the findings for KQ 2 and 3 to identify the strengths and weaknesses of currently funded CBPR and highlight some of the challenges that CBPR researchers face. As noted earlier, we also reviewed articles identified from the literature that addressed existing funding mechanisms specifically focusing on CBPR.

Some articles described broader challenges faced by CBPR researchers and the benefits that may accrue from such research to both communities and investigators.[2,11,53] Other articles addressed future research and funding priorities that included CBPR, such as those for the National Institute on Disability and Rehabilitation Research (NIDRR),[63] or the challenges of securing funding to sustain CBPR efforts.[64]

We also reviewed Web sites and talked with individuals in federal agencies about issues of generating requests for applications (RFAs) for grants and of reviewing and funding CBPR proposals. We focused the Web search and discussions primarily on agencies and their study (review) sections associated with translational research, which we thought to be the most likely recipients of CBPR submissions. These include translational grants sections of the National Institute for Diabetes, Digestive, and Kidney Diseases (NIDDK), National Institute of Environmental Health Sciences (NIEHS) and the Demonstration and Education section (R18) for the National Heart, Lung and Blood Institute. With the Centers for Disease Control and Prevention (CDC) we reviewed and discussed the recently funded RFA "Community-Based Participatory Prevention Research," in 2002 and 2003, 26 grants were funded under this mechanism so the number of CBPR manuscripts submitted and published should rise markedly by the end of this decade.

Finally, we learned more about the Interagency Working Group for Community-Based Participatory Research initiated by NIEHS and established in February 2002.[60] This group was set up Dr. Olden, Director of NIEHS, inviting other agencies to join in the formation of the Interagency Working Group. The purpose of this group is "to strengthen communication among federal agencies with an interest in supporting CBPR processes in the conduct of biomedical research, education, health care delivery, or policy." As this group is still in a formative stage,

its members expressed considerable interest in the results of this evidence review as a guide to their future efforts.

Key Question 1: Definition of Community-Based Participatory Research

Overview

Through our synthesis of verbatim abstractions from 55 articles entered onto the matrix of CBPR domains, we derived a summative definition of CBPR, which is deliberately short to be workable. This definition guided our work; we believe that it can serve the purposes of AHRQ, sponsor of this evidence report, other federal agencies that extensively support CBPR, and other interested parties and agencies.

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 emphasizes (1) co-learning about issues of concern and, within those, the issues that can be studied with CBPR methods and reciprocal transfer of expertise; (2) sharing of decisionmaking power; and (3) mutual ownership of the products and processes of research. The end result is incorporating the knowledge gained with taking action or effecting social change to improve the health and well-being of community members.

The following sections present the results from our systematic review of the literature in this area, which formed the basis for the definition. Of particular concern are the essential elements of community participation, the essential elements of research, and the best practices in these types of investigations. Other key issues concern the outcomes expected from the perspectives of both the community and the investigators.

Essential Elements of Community Participation

According to all 55 articles we reviewed for this key question, participation in the products and process of research by people who experience the issue being studied is considered fundamental to CBPR. Their participation has been justified on the basis of enhanced knowledge production and as a human right. Community members have a right to participate in research because they

- are uniquely qualified and capable to investigate their lived experiences;[65-73]
- should have the opportunity, as co-learners, to generate relevant knowledge and create critical awareness of collective self-reliance that are of immediate and direct benefit;[11,66,74-81] and

- are entitled to own the means of knowledge production and to hold the status and roles of the researcher in relation to the participants.[20]

[53,78,82-88]

Moreover, participation by community members who experience the issue being studied can enhance the quality of the process and products of research by

- providing descriptions, rich in detail, of the local social context and real-world constraints (i.e., replicability), which will improve conceptual robustness and explanatory utility of a study's findings;[78,89,90]
- Establishing congruence between the study and local reality (i.e., increasing face validity), particularly for defining the problem, adapting methodology to specific ecologies and contexts, and determining the nature of acceptable solutions;[75,78,87,89,90] and
- Improving adequate response rates and minimizing attrition because the research question and data collection methods are likely to be context sensitive and culturally relevant (i.e., dependability).[78,88,91]

Community members' participation in research is viewed as a *necessary condition* for the researcher and the researched to (a) redefine their relationship, (b) discover new understanding of the situation and their options, (c) make choices, (d) reduce frustration with past failed attempts, and thereby, (e) build their collective capacities to improve health and well-being of community members.[11,66,72,75-79,85] As a necessary condition, participation in CBPR has been characterized as a concept with multiple dimensions, a process with several modes, and a core value of democracy.

Democratic systems of decisionmaking give a central place to participation in open discussion by guaranteeing public reasoning and deliberative interactions.[67,74] The values placed on participation are tolerance of different points of view, including agreeing to disagree, and the importance of learning from one another.[83] Knowledge development, therefore, is not value-free but rather is political in nature.[67,68,70,71,74,83,86,87,92] That is, power accrues to those who are able to create knowledge and access systems of knowledge that name the problem, organize people and resources around the problem, and mobilize solutions.[67,83,87] Hence, decentralization of power in research decisionmaking is necessary to ensure participation of people who have a stake in the process and products of research, regardless of their status or prior experience with conducting research.

Participation in research of community members affected by the issue being studied has also been defined as a planned and directed process, which can be a social process or a means for empowerment. As a social process, participation is based on theories of group formation and functioning to facilitate open dialogue on divergent views, accommodate conflict, and agree on structures for collaborative decisionmaking.[11,70,83,84,93,94] As a means for empowerment, the purpose of participation is to engage the research group in actively examining the reasons for and consequences from either formal or informal activities of investigation through discussion, whereby needs are identified, decisions are made, and mechanisms are established to improve community life, services, and/or resources.[84,95]

This group process has been described as gradually moving the group through different modes of participation.[73,79] Although not reflective of all CBPR approaches, the four modes of participation, originally conceptualized by Biggs,[96] are as follows:

- *Contractual*: Researchers contract for services (e.g., interviewing) or resources (e.g., time or property) from local people who agree to take part in the research, inquiry, or experiment.
- *Consultative*: Local people are asked for their opinions and advice before the intervention is designed.
- *Collaborative*: Researchers and local people work together on a study that is designed, initiated, and managed by researchers.
- *Collegiate*: Researchers and local people work together as colleagues, each with different skills to offer for mutual learning, to develop a system for independent research among local people.

This notion of gradually shifting control from researchers to local people is also reflected in the literature on participation in research as a process of empowerment. Townsend and colleagues[86] defined empowerment, in a participatory research context, as a process of learning to critique and transform individual feelings, thoughts, and actions, as well as those of the organizations of society, so that the power and resources of research can be shared equitably. Drawing from theories of adult learning (e.g., Freire)[97] and action theory (e.g., Habermas),[98] empowerment is understood as changing not only a participant's personal experience with the power of research but also the power exerted through policies and other forms of institutional control over research.[68,73,78,80,81,83,85-87,92,99]

Nonetheless, local people's participation in research does not guarantee that power and resources will be shifted to them because research partnerships cannot be entirely horizontal.[84] That is, complete equity is constrained by community norms, institutional inertia, and internalized expectations that allow the more powerful participants, however well intentioned, to determine what level of participation at which stage of research is most valuable for whom.[84,99] When participants are conscious of how power is organized by the policies and institutions that govern research, the researchers and the researched are more likely to redefine the power relationship between them.[11,20,70,75,76,78,83,84,93] Whereas, failure to reflect on and openly discuss how power dynamics vary at each stage of research can inhibit meaningful participation and result in a sense of powerlessness and cynicism, when the many tasks involved with research become burdensome or unfeasible, and when the results do not meet expectations.[73,84]

Suggestions to researchers for potential collaborators include

- professional staff at a workplace, such as medical practitioners, health and human service workers, and therapists;[65-68,75,80,84,86,100]
- representatives of local organizations or agencies, such as managers, supervisors, nonprofessional workers, and clients;[11,74,81,86,94,100-103] and
- members of a local community, such as citizens, residents of a neighborhood or hamlet, and members of community-based organizations.[11,56,69,73,74,79,81,87,88,99-101,104]

Participants from one or all of these three categories can serve as researchers and research collaborators. The rationale is that research needs such collaborators for two additional reasons: (1) to gain entry into the world of the people who experience the issue being studied, and (2) to instill accountability and responsibility for what researchers learn to see.[66,67,87] Researchers can maximize reciprocity for the construction and validation of instruments, findings, and conclusions by examining the multiple world views on the issue that collaborators provide.[87]

Participatory research that is community based, such as CBPR, emphasizes enlarging the role and representation of communities as collaborators.[11,56,59,76,83,101] Community, as a collaborator, has been defined as a unit of identity, which is a social and cultural entity that can actively engage and influence its members in all aspects of the research process. Within any local area, people associate through multiple and overlapping networks with diverse linkages based on different interests.[11,20,59,90] This emphasis on community comes from the view that, for lay people, their community holds the strongest potential for collective power to negotiate the production and use of knowledge with the institutions and systems that govern the research enterprise.[11,56,59,76,83,90,100]

Hence, for our evidence report on CBPR, we reviewed studies that included among their collaborators any of the following types of groups: community-based organizations and their executive directors, community as a unit of identity, community residents, clients served by an organization, or nonprofessional workers at a worksite. Many of these studies also included professional and management staff of professional organizations as collaborators. Therefore, we excluded from our review studies that collaborated solely with professional and management staff of professional organizations.

Essential Elements and Best Practices for CBPR Research

The field of public health generally agrees that CBPR is a collaborative process and approach to research for learning about health and illness while contributing to the good health of a community with whom the research is being conducted.[11,56,67-70,72,77,78,81,86,90,92,94,99] However, disagreement arises about whether the stages of research and methods of inquiry of a collaborative approach are the same as those of conventional research[69,83] or distinctively different.[84,87,92]

Nonetheless, consensus does exist on the distinguishing characteristics of a collaborative approach to research. The two core ideas are (1) the reciprocal co-learner relationship between the researcher and the researched[20,67-70,76,78,85,87] and (2) the immediate and direct benefit of using new knowledge for taking collective action and effecting social change.[11,65,66,71,74,81-83,89,90,93,94]

Establishing a reciprocal co-learner relationship is viewed as a systematically planned encounter between researchers and their community collaborators during each stage of research. In this, they (a) meet face-to-face to define their relationship, (b) enter into dialogue on the requirements for equalization of power in the processes and products of research, and (c) set, alongside each other, their respective legitimate knowledge and expertise for examining and addressing a particular issue.[68,76] The criteria for determining the quality of a reciprocal co-learner relationship, put forth by Badger,[75] are

- *Reflexive validity*: Recognizing and exploiting how researchers and a community's respective experiences, values, and actions have affected the research situation and interpretation of findings.
- *Dialectical validity*: Constant analysis and report of movement between theory, research, and practice by examining tensions, contradictions, and complexities of the research situation.
- *Critical validity*: Analyzing the process of change, intentions, actions, ethical implications, and consequences.
- *Face validity*: Subjective judgment of researchers and community that findings appear to fit reality.

Moreover, the three potential uses of research that may be of immediate and direct benefit to a community collaborator have been defined as conceptual, instrumental, and persuasive.[84] Conceptual uses of research aim to change the way people think about problems and their solutions. The experience of collaborating in research can help communities better understand change-related processes, such as the politics of information utilization in change efforts, or the social context in which definitions of the problem are created and revised.[70,71,73,83,87,89] Instrumental uses occur when the results dictate direct changes in existing programs or services.[11,59,69,72,78,81,83,89,90,92,94,99,105] Persuasive uses of research gather sufficient evidence to support a particular position or to influence policy.[53,74,80,82,83,85-89,93,99]

Therefore, the essential research elements of a collaborative approach have been categorized below under its two distinctive characteristics: (1) the reciprocal co-learner relationship between researchers and communities, and (2) the immediate and direct use of new knowledge for taking collective action and effecting social change. With regard to "best practices" for each research element, which are derived through empirical testing, we report on *recommended guidelines* for operationalizing each element from our review of 55 articles that are conceptual rather than empirical.

Reciprocal Co-Learner Relationship. The first important element in this category holds that a structure or mechanism is created for shared decisionmaking between researchers and community. Examples from the literature include a community advisory board, technical advisor group, task force, planning committee, evaluation committee, coordinating committee, or steering committee.[56,57,70,78,80,81,84,89,102,106] Such decisionmaking bodies must develop and then operate under guiding principles for collaboration.[56,57,78,106] The rationale is that in any collaborative relationship, conflict and contradictions are not only inevitable, but in fact are necessary for moving forward with trust building, power dynamics, and accommodating conflict at every stage of the research.[83,93]

Another important element is that the study be designed to remove previous barriers to community participation in research. Some public health scholars and practitioners assert that minimal direct benefit accrues to communities that have given their time, resources, and good will to a study that has "pathologized" them.[68,73,87] That is, when research pathologizes social problems, the common outcomes are individually focused solutions (as opposed to community-focused) controlled by noncommunity entities, thereby once again disenfranchising communities.[73,87]

To remove barriers to community participation in research, the following guidelines have been recommended:

- Offer educational experiences, such as "vision workshops," for both researchers and communities to understand resources and strengths of local people; generate awareness of shared concern with the problems inhibiting social progress of a community; transfer new skills during the research process; and discuss the details of research methods and tensions of matching experimental designs with community action.[70,74,76,93,107]
- Hold group meetings and structured interviews to ascertain concerns about research and discuss methodological options, given a community's resources.[82]
- Hire local coordinators.[107]
- Make written plans detailing types of expertise required at each stage of research.[102]
- Create issue-specific operational mechanisms, such as ad hoc groups, for internal review of operations and measures of accountability.[70,102,106]
- Appoint researchers as guardians of the data *during* the study, and assure guardianship to the community at the end of the study. However, the shared decisionmaking body is obligated to offer original researchers the opportunity to continue analysis before it offers data to new investigators, and the latter must agree to follow guiding principles of collaboration established by the research partners.[78]
- Evaluate the collaborative processes involved throughout the cycle of problem analysis, intervention design, implementation, and institutionalization.[90]

Immediate and Direct Use of New Knowledge. Several considerations arise in thinking about how new knowledge from CBPR work should be applied. First, socioeconomic determinants of health are assessed, addressed, or both. The purpose of assessing and addressing such determinants is to engage researchers and communities in examining how people's personal experiences with health disparities are linked to policies, social structures, and other forms of institutional control.[86] To assess socioeconomic determinants of health, experts have suggested two research strategies as best practices. One is for the study to take an ecological perspective on health so that it generates a holistic understanding of the power that systems exert on everyday life.[11,79] Another strategy is to conduct a power analysis that examines where there is systematic disadvantage, failure to advocate, or merit that is not being recognized or acknowledged.[83] The new knowledge can then be incorporated into the study's problem definition and development of a conceptual framework. The eventual design of a multilevel intervention would address, for example, training families to monitor and protect their homes from air pollutants. The intervention might also include organizing affected communities to present their findings to legislative bodies and advocate for changing policy that is biased toward locating polluting industry near rural communities that are often poor and home to people of color.[88]

Second, the research team should be cognizant and respectful of community needs and priorities during the study's implementation. A high degree of cooperation and flexibility between researchers and communities can be achieved through the best practice of building regular "feedback loops" into the stages of research, one step at a time, and directly reflecting evidence from the previous step.[66,84,94] To be flexible to community needs and priorities, movement through the stages of research is cyclical, repetitive, and iterative.[11,66,94]

Feedback loops create forums for meaningful discussion between researchers and communities on significant community issues, which can also help overcome distrust.[56,75] A reflexive discussion is one in which researchers and their community collaborators acknowledge that their respective experiences, actions, and values have affected the situation and its interpretation.[75] For example, a community may see different uses for the data than what was originally planned. This issue could be addressed at the next scheduled feedback session with a committee specifically formed for this purpose to enhance the research team's flexibility in addressing unforeseen needs and priorities.[84] Moreover, the research team's flexibility will enable them to adjust to the pace at which a collaborative research approach can proceed with success.[74]

Third, the study's duration and purpose contribute to capacity building among individual researchers and their institutions as well as among individual participants or their larger community. Researchers taking a collaborative research approach have an obligation to maintain a long-term relationship of trust in their dual role of researcher-educator, with the purpose of capacity building.[11,78] Four stages of building collective capacity have been recognized: (1) identifying common ground; (2) establishing self as a community player with an issue-based agenda; (3) working on a common project; and (4) working on a multiagency, multisector project.[92] Through a collaborative research approach, capacities that can result include those related to formation of critical consciousness of their unrealized capabilities and potential, improvement of the lives of those involved in the study, and reformation of underlying political structures.[82]

Fourth, formation of critical consciousness of their situation to find answers to unrealized capabilities and potential is another important element of use of new knowledge. Participants' sense of isolation or alienation is reduced by being engaged in systematic discussion and reflection during the study. By focusing on their community, residents' awareness of their shared strengths and concerns is increased.[82,93]

Fifth, improvement of lives of those involved in the study means that residents' unique knowledge of what will work in their community is integrated into information sharing and problem solving during the study. Increasing participants' power to claim a larger share of decisionmaking for their community makes it more likely that findings can be applied to address the health and social issues raised as a result of the research. Community participants can increase control over their lives by nurturing community strengths and problem-solving abilities.[11,69,78,82,93,100]

Sixth, reforming underlying political structures is another key action. The ultimate goal of a collaborative research approach is to change social structures, dealing with institutional control and conflict.[66] The acts of creating knowledge and using it to communicate a community's perspective to policymakers are fundamentally about the right to speak.[82] Although these steps may not guarantee shifting power to communities to decide on policy, a community's capacity to interact directly with policymakers is a necessary first step toward understanding and changing oppressive situations.[73,82,88]

Finally, findings should be (1) used to address the original health concern, (2) disseminated and interpreted to participants, (3) applied to a health-related intervention or policy change, and (4) used to sustain research-related interventions by the community. When new knowledge is

constructed from multiple perspectives and meanings, differences in interpretation of findings are inevitable and intellectual growth can occur.[84] Hence, community collaborators must remain fully involved with decisions on what, where, when, to whom, and how to disseminate findings, apply them toward an action, and sustain them.[82] Products for dissemination include advocacy documents for relevant agencies and authorities, mass media reports, training manuals, and scientific papers and manuscripts.[84] To ensure full collaboration in co-authoring communications about findings, experts recommend developing dissemination guidelines.[78] Before submitting manuscripts or presenting at conferences, co-authors discuss findings with the study's shared decisionmaking body. Any collaborator who disagrees with the interpretation or method of dissemination is invited to submit an alternative interpretation as an addition to the main communication, albeit written or oral, to be submitted at the same time. No single collaborator has the power of veto.

Macleod offers the following recommendations for disseminating findings:[84]

- Frame results to limit potential for blaming people for their problems.
- Communicate results openly, even when some stakeholders will not benefit.
- Establish and maintain credibility of persons who conducted the research.
- View feedback and dissemination as an on-going process of dialogue with stakeholders.
- Be aware of political considerations behind feedback from stakeholders.
- Stay as jargon-free as possible, even with well-trained audiences.
- Use oral presentations as a means for assessing the validity of findings.
- Develop a task force of community members to study any recommendations.

With regard to application of findings, we examined the three potential uses of research described earlier (i.e., conceptual, instrumental, and persuasive).[84] Conceptual application of the findings involves developing theory that is sensitive to a community's context and culturally relevant. Through understanding the social contexts in which findings are applied, the public health field can move toward developing better theories of the problem.[70,71,73,83,87,89] Instrumental application of the findings includes documenting the process by which the findings are used in designing interventions or effecting social changes that attempt to solve public health problems.[2,11,59,69,72,78,81,83,89,90,92,94,99] When the application of findings begins and ends with the behaviors of individuals, however, it is not considered social change (i.e., persuasive).[87] Persuasive application of findings alters the structure, policies, and other forms of institutional control over a community or individual's health and well-being.[53,74,80,82,83,85-89,93,99]

We detected disagreement on how a collaborative research approach contributes to the sustainability of research-related interventions. Some conclude that a long-term commitment by all collaborators is necessary.[11,56,69,74,78,90] For others, however, achieving community autonomy or self-reliance is necessary for sustaining interventions that emerged from the study.[79,80]

Expected Outcomes from the Community and Research Perspectives

A few scholars note that outcomes from a collaborative research approach include those of a capacity-building intervention.[78,82] Inclusiveness of community residents in learning to integrate questioning with reflection, which is the power of research, enables them to challenge and

increase the power of conceptualizing the problem, selecting methodology, defining goals and objectives, securing funding, training trainers, sampling and recruiting participants, constructing measures, conducting analysis, interpreting results, disseminating findings, and advocating for policy change.[53,56,59,69,73,77,80,81,86,88,103,108] Hence, because the data are "grounded" in the experiences of people living along the margins of health and well-being, the findings are more likely to lead to collective action for structural and personal change.[71,86,94,109-111]

At the same time, this grounding in a community's local context can increase the face validity of findings on disparities in health status and practices. Arguably, problem definition, measures, and acceptable solutions need to be connected to social determinants of health; in other words, broad political and economic processes that have drawn capital, people, services, and other resources from low-income, rural, and inner-city communities.[75,78,87,89,90,112] Moreover, by enabling the decisionmaking power of a community to determine with researchers the most context-sensitive and culturally relevant methodology, CBPR approaches can raise the dependability of findings for identifying priorities and possible solutions. The reason is that eligibility criteria, recruitment strategy, data collection methods, and analysis procedures will reflect indigenous mechanisms and structures for communicating information and opinions and exerting influence.[78,88,91] Finally, including community collaborators can increase the replicability of findings on health improvements. Replication by others is more likely to follow from documenting the details of *how* behavioral and social change processes, which are conceptually robust and have explanatory utility, combine resources beyond a community with the competencies, influence, and other assets embedded in a community.[78,89,90,112]

Key Question 2: Implementation of Community-based Participatory Research

Key Question 2 asks how CBPR has been implemented with regard to the quality of research methodology and community involvement. In answering this question, we first provide an overview of the studies identified through this review. We then provide a summary of the implementation of CBPR methodology with respect to study design, measurement, and data collection and analysis. Finally, we provide a summary of different elements of community involvement reported by these studies.

Overview of CBPR Studies

To answer KQ 2, we drew from the 60 studies identified as CBPR. To be included, articles were required to use basic community participation methods and to include some element of data collection and analysis, be it quantitative or qualitative. This is not an exhaustive list of all CBPR studies ever published; we suspect several other studies may exist that we could not identify because of the limitations of MEDLINE indexing terms, the nature of this literature and the work it represents, and our systematic review methodology.

Many of the studies reviewed in this report comprise multiple citations; to allow for both readability and easy access to the complete list of citations, we provide the full study name, the

abbreviated name by which we refer to the study in this review, and the complete list of citations in Table 4. When we cite the study for the first time in the text, we cite all references; thereafter, we use the abbreviated study name. Table 5 summarizes the numbers of these 60 studies with certain characteristics related to populations, clinical or social topics, and similar matters. These points are discussed in more detail in the following sections.

Number and Time Between Publications. 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. This suggests a skewed distribution, with some studies generating multiple publications over a period of several years. By design, some CBPR studies include both a focus on an intervention and an evaluation of the intervention. The complexity of CBPR collaborations combined with journal restrictions on the length of the article 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. Not counting the East Baltimore Health Promotion Study, which spanned 17 years between the first publication and the last, the 24 studies with more than one publication took about 2.5 years from the first publication to the last. Because several of these studies were not completed as of late 2003, we believe that our findings likely understate both the average number of articles generated by a study and the average length of time taken to publish the results.

Period of Research and Publication. The number of CBPR studies has increased sharply in recent years, especially since 2000, and the trend is likely to continue. This phenomenon may be attributable to several critical incidents. With the launching in 1998 of the federal Department of Health and Human Services' Initiative to Eliminate Racial and Ethnic Disparities in Health by the Year 2010, national attention has generated an environment for innovation in public health research and practice for achieving the Healthy People 2010 objectives. Public and private funding institutions have been sponsoring special funding mechanisms, which explicitly require proposed studies to take a CBPR approach. A federal Interagency Committee has been formed to advance the use of CBPR; it involves the National Institutes of Health (NIH), CDC, AHRQ, Department of Agriculture, Housing and Urban Development, Federal Highway Administration, Agency for Toxic Substances and Disease Registry, National Science Foundation, and Environmental Protection Agency.[60] Most recently, the 2003 Institute of Medicine Report, *Who Will Keep the Public Healthy? Educating the Public Health Professionals for the 21st Century*, identifies the use of CBPR as one of eight areas of critical importance in which all public health professionals need to be trained.

Substantive Health Concerns. Several studies took a broad approach to defining health, and these studies constituted the largest group in this literature base. Among studies that took a narrower focus, environmental health was the leading concern because of NIEHS' long-standing interest in CBPR.

Communities of Interest. The definition of community typically included elements of both sociodemographic characteristics and location. Of these 60 studies, the highest proportion of studies (24 studies, or 40 percent) defined their community primarily along racial and ethnic lines, followed by health concerns (18, or 30 percent), location (12, or 20 percent) and occupation (5, or 8 percent).

Among the 24 studies that defined community primarily through race and ethnicity, eight focused on Native Americans, five each on African-Americans, Latino and Asian populations, and one on multiple ethnic groups. Of note, studies conducted with communities of color concentrated on those of low socioeconomic status, using a combination of indicators, such as level of education completed, median family income, health insurance coverage, enrollment in entitlement programs, or English language skills.

Funding. We were able to determine funding sources for 55 of the 60 studies. The majority (53 percent) of these studies reported a single funding source, but a significant minority (33 percent) mentioned at least two funding sources. Several studies were funded by a few key CBPR funding mechanisms. They include the Urban Research Centers, previously funded by the CDC and Environmental Justice and Community-Based Participatory Research in Environmental Health of the NIEHS.

A total of 75 funding sources could be classified as federal or national funding, state funding, foundation or private funding, or university funding. Government agencies at the national level were the predominant source of support; of these, NIEHS and CDC were the two most commonly named funders. Foundations or private sources of funding such as the Kellogg Foundation and the Robert Wood Johnson Foundation also played a significant (albeit smaller) role in supporting CBPR, followed by state agencies such as local departments of health and universities.

Implementation of CBPR: 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. To assess fairly the actual study design, measurement, and data collection and analysis across studies, we considered it necessary to separate studies that implemented and evaluated planned interventions from those that were nonintervention. Noninterventional studies necessarily have different study aims and reporting standards than interventional studies. Similarly, we thought it necessary to distinguish those studies that had completed and fully reported the results of their interventions from those that had not. The following three subsections describe these separate bodies of literature. Tables 6, 7, and 8 present study design and data collection methods for the studies in the completed intervention, not completed or fully evaluated, and noninterventional groups, respectively.

Studies That Implemented and Evaluated Interventions. Table 6 lists the 12 studies that completed evaluated interventions. They are listed by study design and then alphabetically. Although these research teams used several study designs to evaluate interventions, experimental and quasi-experimental designs were used more frequently than nonexperimental methods. Table 6 provides citations, study design, intervention and key results. In addition, it gives two quality grades, one for research design and one for elements of community-based participation. Quality grades could range from 1 to 3, with higher scores reflecting better studies.

Of the 12 studies in this category, four were randomized controlled trials (RCTs); they include Communities Mobilizing for Change on Alcohol or CMCA,[113-118] East Baltimore Health Promotion;[119-122] Health is Gold,[123] and the Sierra Stanford Partnership.[124,125] Five of the 12 were quasi-experimental studies; these include HIV Testing and Counseling for Latina Women;[126-130] Internet Access and Empowerment;[131] the Korean Study Breast and Cervical Cancer Screening Intervention;[132,133,133,134] the Okanagan Diabetes Project,[135] and the Wai'anae Cancer Research Project.[136-138] Studies with nonexperimental designs include the New York Immunization Project[139] and the Stress and Wellness Project,[32,140-143] and Women Dedicated to Demolishing Denial: HIV Risk Reduction for Lesbians and Bisexual Women.[144,145] One of three nonexperimental studies was a one-group pretest and posttest study (NY Immunization); another was a nonexperimental design with data collection throughout the period of the intervention, (Women and HIV Denial); and the third was initiated with a nonexperimental design (Stress and Wellness), but because of changes in operations at the study site, it eventually became a natural experiment comparing two sites, with pretest and posttest data.

The predominant data collection method was quantitative. Five studies used a combination of qualitative and quantitative data collection methods (HIV Latina, Internet Access, Okanagan, Wai'anae, and Stress and Wellness); and one used only qualitative methods (Women and HIV Denial). Two studies mentioned blinded data collection (Sierra Stanford and Stress and Wellness).

Two studies reported that they changed their measures, based on input from community members, to be more culturally relevant (Wai'anae and Korean Study). Three other studies mentioned that they applied instruments that had been previously used in the literature (Internet Access, Stress and Wellness, and Sierra Stanford), but it is unclear whether these were previously validated instruments.

All the studies in this category reported multiple primary variables and outcomes. All but one (Internet Access) assessed socioeconomic determinants of health.

All studies using experimental, quasi-experimental, and one-group pretest and posttest designs reported the statistical significance of their findings. Of the five studies that used qualitative data either alone or in combination with quantitative methods (HIV Latina, Internet Access, Okanagan, and Stress and Wellness), two (Stress and Wellness and Wai'anae) mentioned that community members checked results as a way of verifying the findings with participants. Four studies used a triangulation of data sources (such as medical records, surveys of multiple interest groups and media records) to validate their conclusions (CMCA, East Baltimore, Stress and Wellness, and Okanagan).

Interventions Either Not Completed or Not Fully Evaluated. In the absence of clear information on implemented study design, we classified these studies based on the intended study design. This group of studies (see Table 7) 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,[146-148] PRAISE!,[149,150] Seattle King County Healthy Homes Project[151] and Seattle King County Vaccines[152]); one was intended to be a quasi-experimental design (TEAL[153]); and 13 were nonexperimental designs (Elderly in Need,[92,154] East Side Village Health Worker Partnership,[106,112,155-163] Haida Gwaii Diabetes

Project,[77] Healthy Homes, Healthy Child,[100,164,165] Kahnawake,[78,166-169] La Vida,[170] Mom Empowerment, Too!,[171] the Nuclear Risk Management for Native Communities Project,[70] Preventing Agricultural, Chemical Exposure in North Carolina Farmworkers (PACE),[172,173] The Partners for Improved Nutrition and Health Project (PINAH),[174] Preventing Halloween Arson,[175] Survival Guide,[176,177] and Women and Heart Disease.[178] Table 7 provides a list of citations, study designs and the intended intervention for these studies. Two of the 13 studies with nonexperimental designs discussed plans for later RCTs to test the effectiveness of the interventions (Survival Guide and PACE).

These 18 investigations published findings from baseline data, formative work, and process data. Among this group of studies, information was generally not sufficient to determine whether they had implemented the intervention as intended, which is an issue of research fidelity. These data are more commonly reported when final outcomes data are presented, so this information gap may be expected to be addressed for some of these studies in the future.

Compared to the fully evaluated interventions, a similar portion of these studies used a combination of qualitative and quantitative methods (39 percent for incomplete interventions, compared to 42 percent for fully evaluated interventions). Many of these projects are ongoing studies and have not yet reported their final outcomes data. On average, the first publication from these studies appeared in the peer-reviewed literature 4.5 years ago, compared to 9 years ago for completed interventions.

Four studies reported that the community reviewed and revised their instruments and concepts (ESVHWP, PRAISE, Seattle Homes, and Survival Guide). Although several studies reported using previously developed instruments, the information was insufficient in most cases to determine whether the instruments had been previously validated. Eight studies reported their intent to use multiple sources of information, including archival records, surveys and focus groups of multiple interest groups, environmental assessments, and clinical data from blood sample and pulmonary function tests (CAAA, PRAISE, TEAL, ESVHWP, Healthy Home, Kahnawake, Preventing Arson, and Survival Guide).

Although no study presented sufficient data to qualify as fully evaluated interventions, 11 studies provided information on findings from analysis of psychosocial data, process evaluation, the research process, or more descriptive aspects of the intervention (CAAA, PRAISE, Seattle Vaccines, Elderly in Need, La Vida, Kahnawake, ME2, PINAH, Preventing Arson, Survival Guide, and Women and Heart Disease).

The Halloween Arson study represents an unusual case in that the intervention was conducted (in response to ongoing violence in Detroit around the Halloween period) by a coalition of community members and organizations without any input from researchers or an evaluation plan. Later, researchers in the Urban Research Center at the University of Michigan retrospectively evaluated the intervention in collaboration with community members. In many research efforts using traditional non-CBPR methods, the community is not likely to be involved in designing the intervention. In this case, however, the researchers were not involved in intervention design but were later called in to use a retrospective research method and analysis strategy.

Noninterventional Studies. Table 8 provides key information on the 30 studies we reviewed that had no clear intervention either implemented or planned. The table provides

citations, study design, and objective for these studies. Of these 30, 27 were nonexperimental and primarily exploratory in nature. The other 3 were observational studies that were designed to permit extrapolation to individuals beyond the study population (African Americans Building a Legacy of Health,[179] Hospice Access and Use by African-Americans,[180] and Oregon Migrant Farm Workers[181,182]). Although these studies are classified as noninterventional for the purposes of this review, these studies may have resulted in the implementation of an intervention as a result of the findings. Several of the studies in this category resulted in significant policy change in either civic or private institutions. For the purposes of this report, these studies are considered to be noninterventional because they were not designed with an explicit intervention, nor did they undertake the evaluation of any intervention that might have resulted from their findings. Because the 30 studies without interventions were varied in the extent to which information was abstractable, we do not present detailed evidence tables; summary information is provided in Table 8.

The purpose of these studies varied and 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[183] and[184] HERE[185]); 8 were explorations of health-related knowledge, attitudes and practices (James Bay Cree Diabetes,[76] TAS Together for Agricultural Safety Project,[186] Perspectives of Pregnant and Postpartum Latino Women on Diabetes, Physical Activity, and Health,[187] The Native Hawaiian Smokers Survey,[188] Controlling Pesticide Exposure to Children of Farmworkers,[189] Hospice Access and Use by African-Americans,[180] Diabetes in East Harlem,[190] and Disability community[191]); 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,[192,193] Positively Fit,[194] Bingham,[195] Housing Options,[196] Madison County,[197] Participatory Action Research for Community Health Promotion[198]).

Ten studies moved beyond problem identification. Of these, six assessed factors influencing risk (Oregon Migrant Farm Workers;[181] Chinese American Elderly with Osteoporosis;[199] Community Health and Environment Program;[200-202] Ethnocultural Communities Facing AIDS;[203-208] The Harlem Birth Right Project,[209] Welcome Home Ministries[210,211]), two examined prevalence (The Glades Health Survey,[212] West Harlem Environmental Action [WE ACT][213,214]), and two examined the impact of environmental or policy change (EJS;[215,216] Evaluation of the Blended Funding Project[217]). 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,[179] Healthy Neighborhoods,[69,218] Participatory Action Research for Hmong Women,[219] South Asian women[220]).

Of the 29 studies in this category that provided information on data collection methods, the majority used qualitative methods either as the sole method, or in combination with quantitative methods (62 percent). In 12 projects, this was the sole data collection approach (Oregon Migrants, Aboriginal, Bingham, Controlling pesticides, Disability community, James Bay, Madison County, Perspectives of Latinas, Positively Fit, South Asian, Welcome Home, and

Housing Options). In another 6 studies, the investigators combined qualitative and quantitative methods (CHEP, ECFA, HERE, Hospice Access, TAS, and Harlem Birth Right). Eleven studies or 38 percent reported using only quantitative methods (AABLH, Chinese Elderly, Diabetes in East Harlem, EJS, EBFP, Healthy Neighborhoods, PAR CHP, Poultry Slaughterhouse, Glades, Native Hawaiian, and WE ACT).

Over half the studies (17 of 30) documented the involvement of the community in making measurement instruments more culturally relevant or mentioned field testing their instruments to improve their reliability (Oregon Migrants, Aboriginal, Chinese Elderly, Diabetes in East Harlem, Disability Community, ECFA, EJS, Healthy Neighborhoods, Housing Options, Hospice Access, James Bay Madison County, Native Hawaiian, PAR CHP, Poultry Slaughterhouse, TAS, and Harlem Birth Right).

Half the studies (15 of 30) presented baseline data, general findings or process evaluation results (Aboriginal, Bingham, CHEP, ECFA, Healthy Neighborhoods, HERE, Hospice Access, Housing Options, La Vida, PAR CHP, Perspectives of Latinas, Poultry Slaughterhouse, South Asian, Harlem Birth Right, and Welcome Home). The rest were primarily descriptions of either the research process or the building the community-research collaboration.

Over a third of the studies (11 of 30) reported the use of multiple sources of evidence to validate their findings (Aboriginal, Bingham, CHEP, Controlling pesticides, ECFA, HERE, Hospice Access, Housing Options, Harlem Birth Right, TAS, and WE ACT).

Finally, many of these studies provided rich qualitative and quantitative data regarding the lengthy process of partnership development between universities and communities. Additionally, the studies described how the collaborative process benefited study design, data collection, and participant recruitment or retention, even if they did not include a formal evaluation of this process.

Level of Community Involvement in the Research Process

We reviewed all 60 studies to record evidence of the level of community involvement in the research process (Table 9). As with other sections of this review, our findings are limited by the information available in the published literature. Therefore, our report of the extent of community involvement is necessarily based on the perspectives of the authors of the published articles, which may not always have included the community partners.

The subsections below discuss specific elements of community involvement. The following analysis will generally begin by presenting the number of studies reporting any community involvement for each of these elements, with a comprehensive list of citations. However, in further analysis that lists the specifics of each element of community involvement, we provide illustrative rather than comprehensive citations. We have employed this approach because we found that in several instances, authors stated the nature of community involvement without providing additional detail. In other instances, we may have detected sufficient ambiguity about the extent of community collaboration to limit our abstraction of the data. The limitations of resources and time prevented us from seeking clarification from the authors in these instances.

Priority Setting and Hypothesis Generation. Twenty-eight studies involved the community in setting priorities and generating hypotheses. Often, community-based organizations were already concerned with an issue before researchers approached the community (e.g., Kahnawake). 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 (James Bay, Survival Guide, CHEP, East Baltimore, HERE, La Vida, PAR CHP, and PAR Hmong); others mainly used community involvement to confirm priorities (Disability Community, NRMNC, Diabetes in East Harlem, and Health is Gold). One article reported a community organization that took the lead role, approaching the researchers about its community's priorities and desired research (WE ACT).

Of the 12 projects that assessed the effectiveness of an intervention, 8 reported community involvement (Sierra Stanford, Wai'anae, Health is Gold, HIV Latina, East Baltimore, Women and HIV Denial, Stress and Wellness, and Korean Study). Despite *a priori* notions that RCTs are less flexible than other study designs and that they tend to be dominated by researchers' concerns, we found that 3 of the 4 RCTs that evaluated interventions involved the community in setting priorities (Sierra Stanford, Health is Gold, and East Baltimore). In the case of the East Baltimore, the interests of community leaders were taken into account following a needs assessment to select hypertension and smoking as specific health issues.

Methods Selection. In all, 50 studies reported involving the community in selecting methods, but such participation occurred on different levels. Most studies reported using an advisory committee that cooperated with the researchers. Some committees reviewed proposed methods and suggested changes in wording or terminology to increase cultural appropriateness (Aboriginal, Madison County, ECFA, EJS, James Bay, and Housing Options).

Several communities were actively involved in designing surveys to emphasize particular issues of interest for the community. In one instance, the Haida Gwaii diabetes project, community involvement resulted in the exclusion of alcoholism, a major topic, because of controversy about the issue within the community.

Another frequently used method of involvement was to pretest surveys in the community. Evaluation of these pretest results led to changes in survey questions and improved clarity and validity (Chinese Elderly, TAS, Oregon Migrants, and ESVHWP). Some studies reported using qualitative results of focus groups or interviews to design an appropriate survey instrument (HERE and Hospice Access).

One group stated that it increased its sample size to address community concerns (Harlem Birth Right). Only one article described a complete change in data collection methods pursuant to community input. Residents of Madison County, for the Madison County study, stated a strong aversion toward surveys because of earlier experiences. Subsequently, the project adopted group interviews as a more acceptable method of data collection.

Proposal Development and Funding. Researchers usually took the lead role in proposal development, using their greater experience in the task of obtaining financial support, and they often applied 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 (WE ACT), the community approached the researchers and initiated the proposal.

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

Study Design and Implementation; Data Collection Tools, Recruitment, and Retention. 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 (PRAISE, Okanagan, Internet Access, ESVHWP, CAAA, and Stress and Wellness). Another community took on a more active role proposing appropriate study designs to researchers (PAR CHP) or steering them away from potentially unsuccessful designs (ECFA). In several cases, community involvement tried to ease recruitment and study implementation by using local staff to administer surveys or interviews (Wai'anae, Seattle Homes, PACE, Disability Community, Okanagan, ESVHWP, Women and HIV Denial, and TEAL) or to act as survey helpers who were fluent in the languages of the target group (HERE).

Fifty studies reported community involvement with respect to recruiting and retaining subjects. Contact with community members generally raised the participation rate (Stress and Wellness, CHEP, EJS, ESVHWP, Oregon Migrants, and Positively Fit).

Community advisory boards or community-based organizations were often actively involved in the recruiting participants. A commonly used strategy of recruitment was to seek participants within the social networks of community members who were involved in the research project (Health is Gold, PRAISE, Okanagan, PINAH, ESVHWP, Native Hawaiian, Disability Community, Seattle Homes, and Internet Access). Sierra Stanford emphasized personal contacts before the enrollment of the participants. One study (PRAISE) added an interim intervention for the delayed intervention control group, following advice of community members who were involved in the study. Another study (Chinese Elderly) changed from door-to-door recruitment to community meetings because team leaders thought that the latter would be more culturally appropriate for this particular community. In the HERE study, a union launched a mini-campaign to raise participation. Recruitment within social networks or the participation of volunteers led to high participation rates but also introduced the risk of selection bias; the latter was not measured directly, however.

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. Even among the 30 studies without a planned intervention (fully evaluated or otherwise), one-third of the studies reported that communities were engaged in designing interventions for the community based on the results (10 of 30).

The magnitude of community involvement varied across these studies. Some researchers used findings of earlier community-based descriptive or exploratory studies as a base for intervention development (Healthy Home, Stress and Wellness, and East Baltimore). Others relied on advisory committees that co-designed the intervention and guaranteed its cultural appropriateness (ME2, PRAISE, Okanagan, PINAH, TEAL, and Health is Gold). Still others involved community organizations with active and creative leadership roles in shaping and

implementing interventions (Sierra Stanford, South Asian, Survival Guide, East Baltimore, NY Immunization, ESVHWP, Stress and Wellness, Women and Heart Disease, ESVHWP, Stress and Wellness, and CMCA).

Two studies (Health is Gold and PRAISE) reported that, as a response to concerns of the community either during proposal writing or after funding, they implemented a delayed intervention for the control group. Another study stated that researchers agreed to implement the intervention sooner than intended after negotiations with its community steering committee (ESVHWP).

Feedback from communities also resulted in changed and adapted interventions to deal with the needs and priorities of the target groups (PACE, PINAH, and Health is Gold). Some studies undertook additional efforts to be flexible in addressing community needs and removing barriers specific to the intervention community that could otherwise have compromised participation or intervention; these steps included providing native speakers, child care, transportation, or small stipends (ME2, South Asian, Survival Guide, Healthy Home, Health is Gold, and Korean Study). One study related a negative impact of community involvement; the Korean Study Breast and Cervical Cancer Intervention could not be fully implemented because of a lack of community staff.

Translation of Research Findings. 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 (EJS, CMCA, and PAR CHP) through the efforts of the community collaborators. EJS 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 CMCA 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. PAR CHP, partly through supporting data from its survey, prompted the city council in the community to pass an ordinance to create nonsmoking areas. Five studies resulted in changes at private institutions or local levels through the efforts of community collaborators (Bingham, Healthy Neighborhoods, HERE, Stress and Wellness, and Poultry Slaughterhouse).

Five studies had the potential for change in policy through the generation of plans addressing the specific health concern (AABLH, ECFA, James Bay, TEAL, and NRMNC). They did not report the impact of these plans, however.

Integration and Sustainability. 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 (CHEP, Oregon Migrants, and Kahnawake) or through local funding (Healthy Neighborhoods, Wai'anae, East Baltimore, and Glades) initiated by community organizations. One screening program reported sustainability as a result of the community's closer contact to health clinics during the research (Korean Study).

Multiple studies reported sustainable changes in policies or other aspects of daily life through the presentation and application of findings (Healthy Neighborhoods, CHEP, CMCA, HERE, Stress and Wellness, NRMNC, Bingham, Poultry Slaughterhouse, Madison County, PAR CHP, and EJS). For example, Healthy Neighborhoods was able to re-establish evening and night bus services and to have tobacco billboards removed. The HERE project managed to reduce the workload of hotel room cleaning staff. Communities also frequently used the CBPR project findings to develop action plans for other programs and to apply for grants (Native Hawaiian, Glades, Survival Guide, Diabetes in East Harlem, and Perspectives of Latinas).

Community Involvement in All Aspects of Research. Of the 60 studies relevant to KQ 2 and 3, three studies reported community involvement in all aspects of the research (Wai'anae, Kahnawake, CHEP, and HERE). Of these studies, one was an evaluated intervention with a quasi-experimental design (Wai'anae); another was an incompletely evaluated intervention (Kahnawake); and two were were nonexperimental studies that did not include any interventions (CHEP and HERE).

Key Question 3: Outcomes of Community-Based Participatory Research

This key question focused on whether CBPR projects have had intended effects in terms of better research, outcomes relating to community capacity, and health outcomes broadly defined. The first issue is addressed essentially through our efforts to grade the quality of the 12 individual studies with completed, evaluated interventions; similarly, the third question about health outcomes relates only to those 12 studies. By contrast, questions about positive outcomes for community capacity reflect results from all 60 studies reviewed for KQ 2 and 3.

Improved Research Quality Outcomes

As discussed in Chapter 2, 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 (recorded in Table 6). Higher scores reflect better quality. The average scores could range from 1 to 3, based on the quality grading form provided in Appendix B. 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 (NY Immunization) and another reported that the CBPR approach pulled staff away from intervention delivery, thus reducing the exposure to the intervention (Korean Study).

Community Capacity Outcomes

Improved community capacity is rarely discussed as the objective of the study or the intervention. However, in describing their CBPR methods, authors clearly considered improved community capacity to be an essential component of the process. 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 biases of the authors who were primarily academic researchers. Only nine studies documented the improved capacity of the researchers and research organization from collaboration with the community (James Bay, CAAA, Health is Gold, Kahnawake, Poultry Slaughterhouse, Disability Community, NRMNC, ESVHWP, and Korean Study). In our review of the definitional literature, however, development of individual investigator and research institution capacity to interact better with the community on research issues is a significant expectation of CBPR.

Seven studies mentioned the communities' enhanced capacity to create change (Poultry Slaughterhouse, HERE, Madison County, Native Hawaiian, TAS, Oregon Migrants, and Stress and Wellness). Increases in community capacity 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 (Haida Gwaii, CHEP, Welcome Home, Stress and Wellness, Healthy Neighborhoods, NRMNC, and ESVHWP). Another positive result was the jobs created by the collaboration (ESVHWP, NRMNC, Wai'anae, and Project TEAL). Skills building (CMCA and East Baltimore) and partnership and coalition development (ESVHWP, Okanagan, and Wai'anae) were other beneficial outcomes of the CBPR activities. 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 (James Bay, Disability community, Korean Study, PRAISE, Sierra Stanford, Healthy Home, WE ACT, Internet Access, NY Immunization, AABLH, Women and HIV Denial, Controlling pesticides, EJS, La Vida, PAR CHP, PACE, and Wai'anae).

Health Outcomes

Among the 12 studies evaluating completed interventions addressing health outcomes, 2 dealt with physiologic health outcomes (East Baltimore and Okanagan). Three studies assessed cancer screening behavior (Health is Gold, Korean Study, and Wai'anae) and four others addressed other types of behavior change, such as alcohol consumption, immunization rates, and safer sex behavior (CMCA, HIV Latina, NY Immunization, and Women and HIV Denial). Finally, three studies measured the impact of the intervention on psychosocial outcomes such as emotional support, empowerment, and employee well-being (Sierra Stanford, Internet Access, and Stress and Wellness).

The four RCTs reviewed all resulted in at least 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 is 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 of the published data on these studies, 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 nonparticipatory research approaches.

Key Question 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, in regard to the criteria and processes to be used for review of CBPR in grant proposals:

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 to Solicit and Review CBPR Proposals

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. For example, the CDC funded three Urban Research Centers in 1995, and NIEHS sponsored two CBPR funding vehicles — Environmental Justice and Community Based Participatory Research in Environmental Health — since 1993. In 2002-2003, the CDC funded 26 new projects under the "Community-Based Participatory Prevention Research" grant mechanism.

Private foundations also support CBPR; the W. K. Kellogg Foundation and Annie E. Casey Foundation are among the leaders in the private sector. The Kellogg Foundation funded a Community-Based Public Health Initiative (CBPHI) in 1991 that included several sites that emphasized community-university-agency partnerships to address health disparities. This program prompted the creation of the Community Health Scholars Program, designed to fund postdoctoral applicants seeking training in CBPR (http://sph.umich.edu/chsp/index.shtml).

The considerable interest at the federal level in funding CBPR is further evidenced by the creation of an Interagency Working Group for Community-Based Participatory Research, which has begun to assemble information about existing funding mechanisms for CBPR.[60] Given the rising interest and monetary support for this work, AHRQ sponsored a national meeting in 2001 to explore the current role of CBPR and how best to foster good proposals and successful initiatives in this arena. Participants at that meeting strongly recommended that AHRQ commission this systematic review of issues relating to CBPR, with a view to clarifying this entire research enterprise for current and potential supporters.

Depending on the agency, CBPR proposals may be reviewed through existing study sections or through a special emphasis panel. Because CBPR is an excellent approach to translational research, study sections designated for this purpose are particularly appropriate. Many parts of the National Institutes of Health (NIH) refer to these as R18 proposals. These 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 Disgestive Kidney Diseases (both of which use special emphasis or ad hoc panels for review).

A new study section within the National Cancer Institute is Community Level Health Promotion. Standing study sections generally require a multiyear tenure by committee members, and they review all grants deemed relevant to their focus. A special emphasis panel or ad hoc committee is assembled specifically for the purpose of reviewing responses to a Request for Application (RFA) or more narrowly defined research area. The advantage of a special emphasis panel is that specific instructions, pertinent to the proposals being reviewed, are sent to reviewers for each meeting. Reviewers selected are also more likely to be content experts with respect to the focus of the RFA.

Reviewers for all proposals generally receive review criteria to guide their efforts. These criteria often follow the framework of the standard proposal format and commonly include such broad sections as Significance, Innovation, Approach (methods), Investigators, Research Environment, Budget, and Human Subjects.

Discussions with individuals from the NIH and CDC who are involved with generating RFAs and refining 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 (with the assumption that guidance arriving with a large box of grants will be less likely to be read) 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 High-Quality Grant Applications

As described above, a few special funding mechanisms to date have focused specifically on promoting CBPR. Perhaps the bigger challenge is to obtain funding for CBPR through more conventional review mechanisms in which reviewers may be less familiar with and perhaps even skeptical about CBPR. Not only will a broader range of funding options for CBPR expand the options for funding CBPR efforts; it can serve to educate other scientists about the potential rigor and "added value" of CBPR.

Conventional Research Criteria

Researchers who are applying for funds to support CBPR often fail to address all the criteria for high-quality *conventional* research, and this may be the biggest mistake in seeking CBPR funding. 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.

CBPR Criteria

In addition to meeting criteria for conventional research proposal review, a proposal based on CBPR should clearly describe the added value that this approach brings. This is particularly important when reviewers can be assumed to be unfamiliar with CBPR, which is still probably a safe assumption. The proposal should not simply describe CBPR criteria; it should also discuss the potential benefits for both research quality and the community. Table 1 provides a detailed framework of CBPR principles and their benefits. This information is also presented in the CBPR Reviewer and Applicant Guidelines (Figure 1).

Guidance for Funding Organizations and Applicants

Based on the results of our literature review, discussion with federal funders, a review of funding agency Web sites, and the criteria for funding outlined above, we have created three concise documents that provide guidance to funding organizations, reviewers, and applicants: *CBPR Reviewer and Applicant Guidelines*, *CBPR Reviewer Checklist*, and *CBPR Requests for Applications and Peer Review*. These materials are included at the end of this chapter as Exhibits 1, 2, and 3, respectively. For a more detailed checklist, we refer the reader to work by Green and colleagues, "Guidelines and Categories for Classifying Participatory Research Projects in Health Promotion," which appraises the extent to which proposals or projects align with principles of participatory research.[221]

Because the grant proposal and review process is somewhat standardized across the U.S. Department of Health and Human Services agencies (using the PHS-398 package, for instance), and because these agencies are likely to involve the most rigorous review process, we elected to use the review criteria generally used by these agencies in developing a prototype guideline document. The *CBPR Reviewer and Applicant Guidelines* document (Exhibit 1) is adapted from NIDDK review criteria for translational research, with components for CBPR that we have added for this particular purpose.

The *CBPR Reviewer Checklist* (Exhibit 2) goes one step further, adding to these guidelines more detail regarding what should be expected in a high-quality proposal involving CBPR. Because this example is modeled on what we might expect or advise for federal research agencies, it may not translate directly to grant review mechanisms that foundations and other funding sources might use. These are highly variable across such funding organizations, but we believe that their review procedures will often include the primary components covered in Exhibits 1 and 2; thus, such organizations could adapt this checklist to their own purposes in a fairly straightforward manner.

Finally, as outlined in *CBPR Requests for Applications and Peer Review* (Exhibit 3), 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 did not lead to a clear recommendation regarding how community members should be involved in the peer review process for CBPR. Some precedent exists for "citizen involvement" on academic and industry advisory committees and review panels for activities such as Institutional Review Boards.

Federal staff, with whom we discussed this issue, reported limited experience with community members on review panels, and they had mixed feelings about the best way to include community representatives in the process.

An underlying concern is the potential discomfort for community members who are put into a situation in which the language and subject matter are quite foreign. One NIH contact described a situation in which community members participated in a review for which no prior orientation had been held to enable them to discuss their respective perspectives. This resulted in a very tense and unproductive session. Thus, on the one hand, without a thorough understanding of research principles, lay persons may find it difficult to understand and contribute to much of the discussion. On the other hand, a community member is uniquely qualified to help reviewers critique the proposed approach to community participation.

In short, more careful and creative thought is needed concerning how to solicit input from community members. Some possible solutions to consider include the following:

- Provide extensive orientation for individual community members serving on review panels.
- Oriente the academic panel members to the role of community members.
- Convene an orientation meeting before the formal review to discuss review expectations, ground rules, questions, and concerns.
- Invite community representatives who have been involved in CBPR and hence are more knowledgeable about research.
- Ask community representatives to read abstracts and participate in the discussion but not to serve as a primary or secondary reviewer.
- Ask community representatives to read abstracts and relevant CBPR components of proposals and be asked to assess those components.
- Ask principal investigators to submit two versions of the proposal abstract: one for a lay audience and one for academics.
- Hold primary reviewers for each proposal responsible for engaging community representatives in the discussion in a positive and nonthreatening manner.
- Require the resulting summary statement to include a section reflecting comments from community representatives, which may increase the likelihood that the primary reviewers will involve community representatives in a meaningful way.

Table 4. Full and abbreviated titles and citations

Acronym	Full Study Name	Study References
Studies that Implemented and Evaluated Interventions		
CMCA	Communities Mobilizing For Change on Alcohol	Wagenaar AC, Murray DM, Wolfson M, et al. Communities Mobilizing for Change on Alcohol: Design of a Randomized Community Trial. J Comm Psychol 1994; Special Issue:79-101.[114] Wagenaar AC, Perry CL. Community Strategies for the Reduction of Youth Drinking: Theory and Application. J Res Adolesc 1994; 4(2):319-45.[117] Wagenaar AC, Toomey TL, Murray DM, et al. Sources of alcohol for underage drinkers. J Stud Alcohol 1996; 57(3):325-33.[118] Wagenaar AC, Gehan JP, Jones Webb R et al. Communities Mobilizing for Change on Alcohol: Lessons and results from a 15-community randomized trial. J Comm Psychol 1999; 27(3):315-26.[116] Wagenaar AC, Murray DM, Gehan JP, et al. Communities mobilizing for change on alcohol: outcomes from a randomized community trial. J Stud Alcohol 2000; 61(1):85-94.[115] Wagenaar AC, Murray DM, Toomey TL. Communities mobilizing for change on alcohol (CMCA): effects of a randomized trial on arrests and traffic crashes. Addiction. 2000; 95(2):209-17.[113]
East Baltimore	East Baltimore Health Promotion Program	Green LW, Levine DM, Deeds S. Clinical Trials of Health Education for Hypertensive Outpatients: Design and Baseline Data. Prev Med 1975; 4:417-25.[119] Levine DM, Lawrence WG, Deeds SG, et al. Health Education for Hypertensive Patients. J Am Med Assoc 1979; 241(16):1700-3.[120] Morisky DA, Levine DM, Green LW, et al. Five-Year Blood Pressure Control and Mortality Following Health Education for Hypertensive Patients. Am J Pub Health 1983; 73(2):153-62.[121] Levine DM, Becker DM, Bone LR, et al. A Partnership with Minority Populations: A Community Model of Effectiveness Research. Ethnic Dis 1992; 2:296-305.[122]
Health is Gold	Health Is Gold! Vietnamese Community Health Promotion Project	Lam TK, McPhee SJ, Mock J, et al. Encouraging Vietnamese-American women to obtain Pap tests through lay health worker outreach and media education. J Gen Intern Med 2003; 18(7):516-24.[123]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
Sierra Stanford	Sierra Stanford Partnership	Koopman C, Angell K, Turner-Cobb JM, et al. Distress, coping, and social support among rural women recently diagnosed with primary breast cancer. Breast J 2001; 7(1):25-33.[124] Angell KL, Kreshka MA, McCoy R, et al. Psychosocial intervention for rural women with breast cancer. J Gen Intern Med 2003; 18(7):499-507.[125]
HIV Latina	HIV Testing and Counseling for Latina Women	Flaskerud JH, Calvillo ER. Beliefs about AIDS, health, and illness among low-income Latina women. Res Nurs Health 1991; 14(6):431-8.[130] Flaskerud JH, Nyamathi AM. Home medication injection among Latina women in Los Angeles: implications for health education and prevention. AIDS Care 1996; 8(1):95-102.[128] Flaskerud JH, Uman G, Lara R, et al. Sexual Practices, Attitudes and Knowledge Related to HIV Transmission in Low Income Los Angeles Hispanic Women. J Sex Res 1996; 33(4):343-53.[129] Flaskerud JH, Nyamathi AM, Uman GC. Longitudinal effects of an HIV testing and counseling programme for low-income Latina women. Ethn Health 1997; 2(1-2):89-103.[126] Flaskerud JH, Nyamathi AM. Collaborative inquiry with low-income Latina women. J Health Care Poor Underserv 2000; 11(3):326-42.[127]
Internet Access	Internet Access and Empowerment: A Community-Based Health Initiative	Masi CM, Suarez-Balcazar Y, Cassey MZ, et al. Internet access and empowerment: a community-based health initiative. J Gen Intern Med 2003; 18(7):525-30.[131]
Korean Study	The Korean Study Breast and Cervical Cancer Screening Intervention	Chen AM, Wismer BA, Lew R *et al*. 'Health is strength': a research collaboration involving Korean Study Americans in Alameda County. Am J Prevent Med 1997; 13(6 Suppl):93-100.[133] Wismer BA, Moskowitz JM, Chen AM, et al. Rates and independent correlates of Pap smear testing among Korean Study-American women. Am J Public Health 1998; 88(4):656-60.[134] Wismer BA, Moskowitz JM, Chen AM, et al. Mammography and clinical breast examination among Korean American women in two California counties. Prev Med 1998; 27(1):144-51. [222]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
Korean Study (continued)		Wismer BA, Moskowitz JM, Min K, et al. Interim assessment of a community intervention to improve breast and cervical cancer screening among Korean Study American women. J Public Health Manag Pract 2001; 7(2):61-70.[132]
Okanagan	The Okanagan Diabetes Project	Daniel M, Green LW, Marion SA, et al. Effectiveness of community-directed diabetes prevention and control in a rural Aboriginal population in British Columbia, Canada. Soc Sci Med 1999; 48(6):815-32.[135]
Wai'anae	The Wai'anae Cancer Research Project	Banner RO, DeCambra H, Enos R et al. A breast and cervical cancer project in a native Hawaiian community: Wai'anae cancer research project. Prevent Med 1995; 24(5):447-53.[138] Matsunaga DS, Enos R, Gotay CC, et al. Participatory research in a Native Hawaiian community. The Wai'anae Cancer Research Project. Cancer 1996; 78(7 Suppl):1582-6.[137] Gotay CC, Banner RO, Matsunaga DS, et al. Impact of a culturally appropriate intervention on breast and cervical screening among native Hawaiian women. Prev Med 2000; 31(5):529-37.[136]
NY Immunization	The New York Immunization Project	Rosenberg Z, Findley S, McPhillips S, et al. Community-based strategies for immunizing the "hard-to-reach" child: the New York State immunization and primary health care initiative. Am J Prev Med 1995; 11(3 Suppl):14-20.[139]
Stress and Wellness	Stress and Wellness Project	Israel BA, Schurman SJ, House JS. Action research on occupational stress: involving workers as researchers. Int J Health Serv 1989; 19(1):135-55.[32] Hugentobler MK, Israel BA, Schurman SJ. An action research approach to workplace health: Integrating methods. Health Educ Q 1992; 19(1):55-76.[140] Heaney CA, Israel BA, Schurman SJ, et al. Industrial Relations, Worksite Stress Reduction, and Employee Well-Being: A Participatory Action Research Investigation. J Org Behav 1993; 14(5):495-510.[141] Baker EA, Israel BA, Schurman SJ. A participatory approach to worksite health promotion. J Ambul Care Manage 1994; 17(2):68-81.[142] Schurman SJ. Making the 'new American workplace' safe and healthy: a joint labor-management-researcher approach. Am J Indust Med 1996; 29(4):373-7.[143]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
Women and HIV Denial	Women Dedicated to demolishing denial: HIV risk reduction for lesbians and bisexual women	Stevens PE. HIV Prevention Education for Lesbians and Bisexual Women: A Cultural Analysis of a Community Intervention. Soc Sci Med 1994; 39(11):1565-78.[144] Stevens PE, Hall JM. Participatory action research for sustaining individual and community change: a model of HIV prevention education. AIDS Educ Prev 1998; 10(5):387-402.[145]
Interventions Either Not Completed or Not Fully Evaluated		
CAAA	Community Action Against Asthma	Clark NM, Brown RW, Parker E, et al. Childhood asthma. Environ Health Perspect 1999; 107 Suppl 3:421-9.[148] Keeler GJ, Dvonch T, Yip FY et al. Assessment of personal and community-level exposures to particulate matter among children with asthma in Detroit, Michigan, as part of Community Action Against Asthma (CAAA). Environment Health Perspect 2002; 110 Suppl 2:173-81.[146] Parker EA, Israel BA, Williams M, et al. Community action against asthma: examining the partnership process of a community-based participatory research project. J Gen Intern Med 2003; 18(7):558-67.[147]
PRAISE	PRAISE!	Corbie-Smith G, Ammerman AS, Katz ML, et al. Trust, benefit, satisfaction, and burden: a randomized controlled trial to reduce cancer risk through African-American churches. J Gen Intern Med 2003; 18(7):531-41.[149] Ammerman A, Washington C, Jackson B, et al. The PRAISE! Project: A church-based nutrition intervention designed for cultural appropriateness, sustainability and diffusion. J Health Promotion Pract In press.[150]
Seattle Homes	Seattle King County Healthy Homes Project	Krieger JW, Song L, Takaro TK, et al. Asthma and the home environment of low-income urban children: preliminary findings from the Seattle-King County healthy homes project. J Urban Health 2000; 77(1):50-67.[151]
Seattle Vaccine	Seattle Vaccine	Krieger JW, Castorina JS, Walls ML, et al. Increasing influenza and pneumococcal immunization rates: a randomized controlled study of a senior center-based intervention. Am J Prev Med 2000; 18(2):123-31.[152]
TEAL	Tribal Efforts Against Lead	Kegler MC, Malcoe LH, Lynch RA, et al. A community-based intervention to reduce lead exposure among Native American children. Environ Epidemiol Toxicol 2000; 2:121-32.[153]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
ESVHWP	East Side Village Health Worker Partnership	Schulz AJ, Israel BA, Becker AB, et al. "It's a 24-hour thing ... a living-for-each-other concept": identity, networks, and community in an urban village health worker project. Health Educ Behav 1997; 24(4):465-80.[163] Parker EA, Schulz AJ, Israel BA, Hollis R. Detroit's East Side Village Health Worker Partnership: community-based lay health advisor intervention in an urban area. Health Educ Behav 1998; 25(1):24-45.[162] Schulz AJ, Parker EA, Israel BA, Becker AB, Maciak BJ, Hollis R. Conducting a participatory community-based survey for a community health intervention on Detroit's east side. J Public Health Manag Pract 1998; 4(2):10-24.[106] Schulz A, Israel B, Williams D, et al. Social inequalities, stressors and self reported health status among African American and white women in the Detroit metropolitan area. Soc Sci Med 2000; 51(11):1639-53.[161] Parker EA, Lichtenstein RL, Schulz AJ et al. Disentangling measures of individual perceptions of community social dynamics: results of a community survey. Health Educ Behav 2001; 28(4):462-86.[159] Schulz AJ, Israel BA, Parker EA, Lockett M, Hill Y, Wills R. The East Side Village Health Worker Partnership: integrating research with action to reduce health disparities. Public Health Reports. 2001; 116(6):548-57.[158] Schulz A, Parker E, Israel DB, et al. Social context, stressors, and disparities in women's health. J Am Med Womens Assoc 2001; 56(4):143-9.[160] Becker AB, Israel BA, Schulz AJ, et al. Predictors of perceived control among African American women in Detroit: exploring empowerment as a multilevel construct. Health Educ Behav 2002; 29(6):699-715.[156] Israel BA, Farquhar SA, Schulz AJ, et al. The relationship between social support, stress, and health among women on Detroit's East Side. Health Educ Behav 2002; 29(3):342-60.[157] Schulz AJ, Parker EA, Israel BA, Allen A, Decarlo M, Lockett M. Addressing social determinants of health through community-based participatory research: the East Side Village Health Worker Partnership. Health Educat Behav 2002; 29(3):326-41.[112]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
ESVHWP (continued)		van Olphen J, Schulz A, Israel B, et al. Religious involvement, social support, and health among African-American women on the east side of Detroit. J Gen Intern Med 2003; 18(7):549-57.[155]
Elderly in Need	Elderly in Need	Moyer A, Coristine M, Jamault M, Roberge G, O'Hagan M. Identifying older people in need using action research. J Clin Nurs 1999; 8(1):103-11.[154] Moyer A, Coristine M, MacLean L, Meyer M. A model for building collective capacity in community-based programs: the Elderly in Need Project. Pub Health Nurs 1999; 16(3):205-14.[92]
Haida Gwaii	Haida Gwaii Diabetes Project	Herbert CP. Community-based research as a tool for empowerment: the Haida Gwaii Diabetes Project example. Can J Pub Health. Revue Canadienne De Sante Publique. 1996; 87(2):109-12.[77] Evans DT, Fullilove MT, Green L, et al. Awareness of environmental risks and protective actions among minority women in Northern Manhattan. Environ Health Perspect 2002; 110 Suppl 2:271-5.[165] Green L, Fullilove M, Evans D, et al. "Hey, mom, thanks!": use of focus groups in the development of place-specific materials for a community environmental action campaign. Environ Health Perspect 2002; 110 Suppl 2:265-9.[100] Perera FP, Illman SM, Kinney PL et al. The challenge of preventing environmentally related disease in young children: community-based research in New York City. Environment Health Perspect 2002; 110(2):197-204.[164]
Healthy Home	Healthy Home, Healthy Child	Green L, Fullilove M, Evans D, et al. "Hey, mom, thanks!": use of focus groups in the development of place-specific materials for a community environmental action campaign. Environ Health Perspect 2002; 110 Suppl 2:265-9.[100] Perera FP, Illman SM, Kinney PL *et al*. The challenge of preventing environmentally related disease in young children: community-based research in New York City. Environ Health Perspect 2002; 110(2):197-204.[164] Evans DT, Fullilove MT, Green L, et al. Awareness of environmental risks and protective actions among minority women in Northern Manhattan. Environ Health Perspect 2002; 110 Suppl 2:271-5.[165]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
Kahnawake	Kahnawake	Macaulay AC, Delormier T, McComber AM *et al*. Participatory research with native community of Kahnawake creates innovative Code of Research Ethics. Can J Pub Health 1998; 89(2):105-8.[78] Macaulay AC, Paradis G, Potvin L *et al*. The Kahnawake Schools Diabetes Prevention Project: intervention, evaluation, and baseline results of a diabetes primary prevention program with a native community in Canada. Prev Med 1997; 26(6):779-90.[166] Potvin L, Cargo M, McComber AM, et al. Implementing participatory intervention and research in communities: lessons from the Kahnawake Schools Diabetes Prevention Project in Canada. Soc Sci Med 2003; 56(6):1295-305.[167] Macaulay AC, Cross EJ, Delormier T, Potvin L, Paradis G, McComber A. Developing a Code of Research Ethics for research with a Native community in Canada: a report from the Kahnawake Schools Diabetes Prevention Project. Int J Circumpolar Health 1998; 57 Suppl 1:38-40.[168] McComber AM, Macaulay AC, Kirby R, et al. The Kahnawake Schools Diabetes Prevention Project: community participation in a diabetes primary prevention research project. Int J Circumpolar Health 1998; 57 Suppl 1:370-4.[169]
La Vida	La Vida	Maciak BJ, Guzman R, Santiago A, Villalobos G, Israel BA. Establishing LA VIDA: a community-based partnership to prevent intimate violence against Latina women. Health Educ Behav 1999; 26(6):821-40.[170]
ME2	Mom Empowerment Too!	Baldwin JH, Rawlings A, Marshall ES, et al. Mom empowerment, too! (ME2): a program for young mothers involved in substance abuse. Public Health Nurs 1999; 16(6):376-83.[171]
NRMNC	The Nuclear Risk Management for Native Communities Project	Quigley D, Handy D, Goble R, Sanchez V, George P. Participatory research strategies in nuclear risk management for native communities. J Health Comm. 2000; 5(4):305-31.[70]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
PACE	Preventing Agricultural, Chemical Exposure in North Carolina Farmworkers	Arcury TA, Austin CK, Quandt SA, et al. Enhancing community participation in intervention research: farmworkers and agricultural chemicals in North Carolina. Health Educ Behav 1999; 26(4):563-78.[172] Quandt SA, Arcury TA, Pell AI. Something for everyone? A community and academic partnership to address farmworker pesticide exposure in North Carolina. Environ Health Perspect 2001; 109 Suppl 3:435-41.[173]
PINAH	The Partners for Improved Nutrition and Health Project	Eng E, Parker E. Measuring community competence in the Mississippi Delta: the interface between program evaluation and empowerment. Health Educ Q 1994; 21(2):199-220.[174]
Preventing Arson	Preventing Halloween Arson	Maciak BJ, Moore MT, Leviton LC, et al. Preventing Halloween arson in an urban setting: a model for multisectoral planning and community participation. Health Educ Behav 1998; 25(2):194-211.[175]
Survival Guide	Survival Guide	Factor SH, Galea S, de Duenas Geli LG, et al. Development of a "survival" guide for substance users in Harlem, New York City. Health Educ Behav 2002; 29(3):312-25.[176] Galea S, Factor SH, Palermo AG, Aaron D, Canales E, Vlahov D. Access to resources for substance users in Harlem, New York City: Service provider and client perspectives. Health Educ Behav 2002; 29(3):296-311.[177]
Women and Heart Disease	Women and Heart Disease	Arthur HM, Wright DM, Smith KM. Women and heart disease: the treatment may end but the suffering continues. Can J Nurs Res 2001; 33(3):17-29.[178]
Noninterventional Studies		
AALBH	African Americans Building a Legacy of Health	Sloane DC, Diamant AL, Lewis LB, et al. Improving the nutritional resource environment for healthy living through community-based participatory research. J Gen Intern Med 2003; 18(7):568-75.[179]
Hospice Access	Hospice Access and Use by African-Americans	Reese DJ, Ahern RE, Nair S, et al. Hospice access and use by African Americans: addressing cultural and institutional barriers through participatory action research. Soc Work 1999; 44(6):549-59.[180]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
Oregon Migrants	Oregon Migrant Farm Workers	McCauley LA, Beltran M, Phillips J, et al. The Oregon migrant farmworker community: an evolving model for participatory research. Environ Health Perspect 2001; 109 Suppl 3:449-55.[182] McCauley LA, Lasarev MR, Higgins G, et al. Work characteristics and pesticide exposures among migrant agricultural families: a community-based research approach. Environ Health Perspect 2001; 109(5):533-8.[181]
Aboriginal	Aboriginal Grandmothers	Dickson G. Aboriginal grandmothers' experience with health promotion and participatory action research. Qualit Health Res 2000; 10(2):188-213.[193] Dickson G, Green KL. Participatory action research: lessons learned with Aboriginal grandmothers. Health Care Women Int 2001; 22(5):471-82.[192]
Bingham	Bingham	Eng E, Blanchard L. Action-Oriented Community Diagnosis: A Health Education Tool. Intnl Quarter Comm Health Educ 1991; 11(2):93-110.[195]
Chinese Elderly	Chinese American Elderly with Osteoporosis	Lauderdale DS, Kuohung V, Chang SL, et al. Identifying older Chinese immigrants at high risk for osteoporosis. J Gen Intern Med 2003; 18(7):508-15.[199]
CHEP	Community Health Environment Program	Ledogar RJ, Acosta LG, Penchaszadeh A. Building international public health vision through local community research: the El Puente-CIET partnership. Am J Public Health 1999; 89(12):1795-7.[200] Ledogar RJ, Penchaszadeh A, Garden CC, et al. Asthma and Latino cultures: different prevalence reported among groups sharing the same environment. Am J Public Health 2000; 90(6):929-35.[201] Corburn J. Combining community-based research and local knowledge to confront asthma and subsistence-fishing hazards in Greenpoint/Williamsburg, Brooklyn, New York. Environ Health Perspect 2002; 110 Suppl 2:241-8.[202]
Controlling Pesticides	Controlling Pesticide Exposure to Children of Farmworkers	Minkler M, Thompson M, Bell J, Rose K. Contributions of community involvement to organizational-level empowerment: the federal Healthy Start experience. Health Educ Behav 2001; 28(6):783-807.[189]
Diabetes in East Harlem	Diabetes in East Harlem	Horowitz CR, Williams L, Bickell NA. A community-centered approach to diabetes in East Harlem. J Gen Intern Med 2003; 18(7):542-8.[190]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
Disability Community	Disability Community	Minkler M, Fadem P, Perry M, Blum K, Moore L, Rogers J. Ethical dilemmas in participatory action research: a case study from the disability community. Health Educ Behav. 2002; 29(1):14-29.[191]
EJS	Environmental Justice Study	Wing S, Wolf S. Intensive livestock operations, health, and quality of life among eastern North Carolina residents. Environ Health Perspect 2000; 108(3):233-8.[215] Wing S, Cole D, Grant G. Environmental injustice in North Carolina's hog industry. Environ Health Perspect 2000; 108(3):225-31.[216]
ECFA	Ethnocultural Communities Facing AIDS	Adrien A, Godin G, Cappon P, et al. Overview of the Canadian study on the determinants of ethnoculturally specific behaviours related to HIV/AIDS. Can J Public Health 1996; 87 Suppl 1:S4-10.[203] Willms D, Bhatia R, Lowe J, Niemi F, Stewart D, Westmoreland-Traore J. Five conversations: reflections of stakeholders on the impact of the ethnocultural communities facing AIDS study. Can J Public Health 1996; 87 Suppl 1:S44-8, S49-53.[204] Willms D, Singer SM, Adrien A, et al. Participatory aspects in the qualitative research design of phase II of the ethnocultural communities facing AIDS study. Can J Public Health 1996; 87 Suppl 1:S15-25, S16-27.[205] Singer SM, Willms DG, Adrien A, et al. Many voices--sociocultural results of the ethnocultural communities facing AIDS study in Canada. Can J Public Health 1996; 87 Suppl 1:S26-32, S28-35.[206] Maticka-Tyndale E, Godin G, LeMay G, et al. Canadian ethnocultural communities facing AIDS: overview and summary of survey results from phase III. Can J Public Health 1996; 87 Suppl 1:S38-43, S42-8.[207] Cappon P, Adrien A, Godin G, et al. HIV/AIDS in the context of culture: selection of ethnocultural communities for study in Canada. Can J Public Health 1996; 87 Suppl 1:S11-4, S11-5.[208]
EBFP	Evaluation of the Blended Funding Project	Vander Stoep A, Williams M, Jones R, Green L, Trupin E. Families as full research partners: what's in it for us?. J Behav Health Serv Res. 1999; 26(3):329-44.[217]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
Glades	The Glades Health Survey	Stratford D, Chamblee S, Ellerbrock TV, et al. Integration of a participatory research strategy into a rural health survey. J Gen Intern Med 2003; 18(7):586-8.[212]
Harlem Birth Right	The Harlem Birth Right Project	Mullings L, Wali A, McLean D, et al. Qualitative methodologies and community participation in examining reproductive experiences: the Harlem Birth Right Project. Matern Child Health J 2001; 5(2):85-93.[209]
HNP	Healthy Neighborhoods Project	el-Askari G, Freestone J, Irizarry C, et al. The Healthy Neighborhoods Project: a local health department's role in catalyzing community development. Health Educ Behav 1998; 25(2):146-59.[218] Minkler M. Using Participatory Action Research to build Healthy Communities. Public Health Rep 2000; 115(2-3):191-7.[69]
HERE	HERE	Lee PT, Krause N. The impact of a worker health study on working conditions. J Public Health Policy 2002; 23(3):268-85.[185]
Housing Options	Housing Options	Stajduhar KI, Lindsey E. Home away from home: essential elements in developing housing options for people living with HIV/AIDS. AIDS Patient Care Stds. 1999; 13(8):481-91.[196]
James Bay	James Bay Cree Diabetes	Boston P, Jordan S, MacNamara E et al. Using participatory action research to understand the meanings aboriginal Canadians attribute to the rising incidence of diabetes. Chronic Dis Can. 1997; 18(1):5-12.[76]
Madison County	Madison County	Plaut T, Landis S, Trevor J. Enhancing Participatory Research with the Community Oriented Primary Care Model: A Case Study in Community Mobilization. Am Sociol 1992; 56-70.[197]
Native Hawaiian	The Native Hawaiian Smokers Survey	Tsark JA. A participatory research approach to address data needs in tobacco use among Native Hawaiians. Asian Am Pacific Islander J Health. 2001-2002; 9(1):40-8.[188]
PAR CHP	Participatory Action Research for Community Health	Rains JW, Ray DW. Participatory action research for community health promotion. Public Health Nurs 1995; 12(4):256-61.[198]
PAR Hmong	Participatory Action Research with Hmong Women	Yoshihama M, Carr ES. Community Participation Reconsidered: Feminist Participatory Action Research With Hmong Women. J Comm Pract 2002; 10(4):85-103.[219]

Table 4. Full and abbreviated titles and citations (continued)

Acronym	Full Study Name	Study References
Perspectives in Latina Women	Perspectives of Pregnant and Postpartum Latino Women on Diabetes, Physical Activity and Health	Kieffer EC, Willis SK, Arellano N, et al. Perspectives of pregnant and postpartum Latino women on diabetes, physical activity, and health. Health Educ Behav 2002; 29(5):542-56.[187]
Positively Fit	Positively Fit	Hiebert W, Swan D. Positively Fit: A Case Study in Community Development and the Role of Participatory Action Research. Comm Devel J 1999; 34(4): Oct, 356-64.[194]
Poultry Slaughterhouse	Poultry Slaughterhouse Study	Mergler D, Brabant C, Vezina N, et al. The weaker sex? Men in women's working conditions report similar health symptoms. J Occup Med 1987; 29(5):417-21.[183] Mergler D. Worker participation in occupational health research: theory and practice. Int J Health Serv 1987; 17(1):151-67.[184]
South Asian	South Asian Women	Choudhry UK, Jandu S, Mahal J, Singh R, Sohi Pabla H, Mutta B. Health promotion and participatory action research with South Asian women. J Nurs Scholarship 2002; 34(1):75-81.[220]
TAS	Together for Agricultural Safety Project	Flocks J, Clarke L, Albrecht S, et al. Implementing a community-based social marketing project to improve agricultural worker health. Environ Health Perspect 2001; 109 Suppl 3:461-8.[186]
Welcome Home	Welcome Home Ministries	Parsons ML, Warner-Robbins C. Formerly incarcerated women create healthy lives through participatory action research. Holistic Nurs Pract 2002; 16(2):40-9.[210] Parsons ML, Warner-Robbins C. Factors that support women's successful transition to the community following jail/prison. Health Care Women Int 2002; 23(1):6-18.[211]
WE ACT	West Harlem Environmental Action	Northridge ME, Yankura J, Kinney PL, et al. Diesel exhaust exposure among adolescents in Harlem: a community-driven study. Am J Public Health 1999; 89(7):998-1002.[214] Kinney PL, Aggarwal M, Northridge ME, et al. Airborne concentrations of PM(2.5) and diesel exhaust particles on Harlem sidewalks: a community-based pilot study. Environ Health Perspect 2000; 108(3):213-8.[213]

Table 5. Summary characteristics of CBPR studies

Characteristics	Number of Studies
Total number of studies identified	60
Average number of publications per study	2
Publication dates of the first article from the study	
Before 1980	1
1980-1985	0
1986-1990	2
1991-1995	8
1996-2000	25
2001 to 2003	24
Substantive topics	
General health concerns	11
Environmental hazards	9
Hypertension/heart disease/diabetes	8
Services for Human Immunodeficiency Virus (HIV)	6
Substance abuse including smoking	5
Cancer screening and prevention	4
Women's health	4
Asthma prevention	2
Occupational health	2
Seniors' health	2
Other miscellaneous concerns (disabilities, hospice access, childhood immunization, nutrition, mental health)	7
Study population or community defined by	
Ethnicity or race	24
Native American	*8*
African-American	*5*
Latino	*5*
Asian	*5*
Multiple ethnic groups	*1*
Health concern	18
Location	12
Occupation	6
Number of funding sources	
None listed	5
1	35
2	18
3 or more	2

Table 5. Summary characteristics of CBPR studies (continued)

Characteristics	Number of Studies
Type of funding sources (of all identifiable funding sources)	
Federal agencies	43
National Institute of Environmental Health Sciences	*11*
Centers for Disease Control and Prevention	*10*
National Cancer Institute	*3*
US Environment Protection Agency	*3*
National Institute on Alcohol Abuse and Alcoholism	*2*
Other agencies	*14*
Foundations or private sources	15
W.J. Kellogg Foundation	*3*
Robert Wood Johnson Foundation	*2*
Other foundations or private sources	*10*
State funding	11
Universities	6

Table 6. Completed interventions

Study Name and Citations	Study Design	Intervention	Key Results	Quality Rating for Research Elements/ Participatory Elements*
CMCA[113-118]	RCT	Community organizers worked with local public officials, agencies, media, and merchants to change community policies toward alcohol	Measures for access to alcohol and drinking behaviors generally declined after the intervention, although only 1 measure showed a statistically significant difference to the control group	2.65/2.45
East Baltimore[119-122]	RCT	Exit interview to increase understanding of disease and compliance with prescribed regimen; home visit to encourage a family member to provide support; invitations to small group sessions	Overall mortality and hypertension-specific mortality declined significantly in experimental groups; intervention shows a positive effect on appointment keeping, weight control, and blood pressure	2.74/2.45
Health is Gold![123]	RCT	Lay health worker activities: two 90-minute sessions with presentations and discussions at baseline, one session after 2 months	Preliminary findings: Percentage of women who had a Pap test increased significantly in the intervention group; knowledge about cervical cancer and Pap tests increased in both groups	2.61/2.60
Sierra Stanford[124,125]	RCT	Community-initiated workbook journal used as a support group alternative	No significant differences between groups in primary outcome measures; however, 74% of women felt emotionally supported	2.83/1.80
HIV Latina[126-130]	Quasi-experimental	Psycho-educational interventions prior to and 2 weeks after HIV antibody testing, including counseling, free condoms, skill development in condom use and cleaning needles, pregnancy counseling, referral, and advocacy	Participants in the intervention group made significant improvements in HIV knowledge and reported condom use, comparison group did not make significant pretest-posttest improvements in these measures	1.78/2.15

Table 6. Completed interventions (continued)

Study Name and Citations	Study Design	Intervention	Key Results	Quality Rating for Research Elements/ Participatory Elements*
Internet Access[131]	Quasi-experimental	Internet access via WebTV, training, technical support; access to a community specific health oriented Web page; placement of public Internet access in 10 community locations	Internet can positively influence health-related empowerment (six of eight items significantly different between intervention and control groups, compared to one item at baseline)	1.83/1.60
Korean Study[132-134,222]	Quasi-experimental	Educational materials and workshops in Korean about breast and cervical cancer screening; written material was also mailed to baseline survey participants	No significant differences in changes in screening between the intervention and the control group	2.43/2.55
Okanagan[135]	Quasi-experimental	A wide variety of activities and education measures based on community assessment of need, aimed at primary prevention, screening, and secondary prevention	Mixed results in changes of biological markers due to intervention effects	2.52/1.65
Wai'anae[136-138]	Quasi-experimental	Kokua Group, lay health educator-led group discussions to provide support and education for breast and cervical cancer screening; vouchers for free mammograms and Pap tests provided to patient and friend	Increased compliance with screening guidelines	2.39/3.00
NY Immunization[139]	One group pretest and posttest	Various outreach strategies to identify and enroll under-immunized children	Coverage rates for the basic antigens increased from 24% to 73% within recruited cohort	1.52/1.78
Stress and Wellness[141-143,223,224]	One group pretest and posttest	Daily newsletter, health awareness and screening programs, information display cases, feedback and recommendations to people on sources of stress, pilot project on quality improvement	Overall, social environment at work and employee well-being did not improve during the course of the study, however involvement in the project was associated with some improvements in decisionmaking, participation, coworker support and decreased symptoms for depression.	2.26/2.90

Table 6. Completed interventions (continued)

Study Name and Citations	Study Design	Intervention	Key Results	Quality Rating for Research Elements/ Participatory Elements*
Women and HIV Denial[144,145]	Nonexperi-mental, (data collected throughout period of intervention)	Individually tailored education based on interview contents, safer sex kits, and presentations at clubs and bars	20% of the women interviewed said that they had changed their behavior	1.52/1.95

* Range = 1 to 3; higher values represent better quality.

Table 7. CBPR studies with incomplete or not fully evaluated interventions

Study Name and Citations	Study Design	Intervention
CAAA[146-148]	Experimental: One group staggered randomized design	Community Environmental Specialists provide education and materials that relate to the reduction of asthma-triggers during home visits (minimum 12 visits)
PRAISE[149,150]	Experimental: RCT	Dietary cancer prevention intervention: 3 workshops on dietary cancer prevention; communication center; quarterly packets; tailored health bulletin; food festival; food events; inspirational booklet; skills assessment of the congregation
Seattle Homes Project[151]	Experimental: RCT	Outreach workers conduct home assessments and develop action plans; educational and social support
Seattle Vaccines[152]	Experimental: RCT	An educational brochure was mailed along with a postage-paid reply card to track immunization status; if response card not received, Senior Center volunteers made telephone contact using a script to encourage receipt of immunizations and to address specific barriers to immunization
TEAL[153]	Quasi-experimental	Only for Native Americans; 40 lay health advisors disseminate information through their social networks
ESVHWP[106,112,155-163]	Nonexperimental	30 lay health advisers (Village Health Workers) focused on increasing the problem-solving capacity of their community to reduce stressors or increase protective factors
Elderly in Need[92,154]	Nonexperimental	Individual interventions through public health nurses focusing on empowering the client and interventions on community levels to increase outreach to elderly residents
Haida Gwaii[77]	Nonexperimental	NR, except for two examples: a walking group and a group to gather traditional foods
Healthy Home[100,164,165]	Nonexperimental	Community education campaign to increase local residents' awareness of environmental health threats and protective techniques
Kahnawake[78,166-169]	Nonexperimental	Elementary school-based program to promote healthy lifestyle
La Vida[170]	Nonexperimental	Interventions were intended to build on local knowledge, details NR

Table 7. CBPR studies with incomplete or not fully evaluated interventions (continued)

Study Name and Citations	Study Design	Intervention
ME2[171]	Nonexperimental	Participatory educational and support program involving a workshop with 16 group sessions, home visits, and case management (support, resource referrals, information); expected outcome of the intervention not clearly stated
NRMNC[70]	Nonexperimental	Educational activities (workshops, presentations)
PACE[172,173]	Nonexperimental	Training package for pesticide safety; health promoter workshops
PINAH[174]	Nonexperimental	Health fairs; clean-up campaigns; teen pregnancy and drug awareness workshops
Preventing Arson[175]	Nonexperimental	Elimination of arson targets; deployment of public safety personnel; youth curfew; volunteer mobilization; activities for children and teenagers; media campaign
Survival Guide[176,177]	Nonexperimental	"Survival guide" for substance users to provide connections to treatment services
Women and Heart Disease[178]	Nonexperimental	Telephone communication network and monthly 2-hour group sessions

Table 8. Noninterventional CBPR Studies

Study Name	Study Design	Research Objective
AABLH[179]	Observational	To build health promotion capacity among community residents through a community-based participatory model and to apply this model to study the nutritional environment of an urban area
Hospice Access[180]	Observational	To identify cultural and institutional barriers of African Americans toward hospices
Oregon Migrants[181,182]	Observational	To examine the degree of exposure to pesticides and potential health effects in migrant farmer workers and their children
Aboriginal[192,193]	Nonexperimental	To conduct a health assessment of older, urban, aboriginal women and support the grandmothers through health promotion programs
Bingham[195]	Nonexperimental	To identify community needs and work with residents in undertaking the solution
Chinese Elderly[199]	Nonexperimental	To assess whether older foreign-born Chinese Americans living in an urban ethnic enclave are at high risk of osteoporosis and to refer participants at high risk for followup care
CHEP[200-202]	Nonexperimental	To understand potential asthma triggers and home remedies and devise culturally relevant interventions
Controlling Pesticides[189]	Nonexperimental	To investigate how farm workers and those influential in farm worker safety shared common perspectives and how these perspectives could be used so groups could work together
Diabetes in East Harlem[190]	Nonexperimental	To survey East Harlem residents with diabetes to assess their knowledge, behaviors, barriers to care, and actions taken in response to barriers
Disability Community[191]	Nonexperimental	To uncover the attitudes of people with disabilities toward death with dignity/physician-assisted suicide legislation
EJS[215,216]	Nonexperimental	To quantify systematically the extent to which livestock operations and their potential impacts on health and quality of life disproportionately affected communities of low income and people of color
ECFA[203-208,225]	Nonexperimental	To identify the information necessary to design programs that reduce the risk of HIV transmission
EBFP[217]	Nonexperimental	To test the effect of the Blended Funding “system of care” on the functional status of children with mental illness, and to test the effects of the project on the ability of families and communities to care for these children
Glades[212]	Nonexperimental	To assess population-based rates of TB and HIV infection in the Glades community

Table 8. Noninterventional CBPR Studies

Study Name	Study Design	Research Objective
Harlem Birth Right[209]	Nonexperimental	To identify the social, economic, and political variables that may lead to high rates of infant mortality and adverse pregnancy outcomes among African American women
Healthy Neighborhoods[69,218]	Nonexperimental	To increase the general health of the community through neighborhood health advocates and action teams
HERE[185]	Nonexperimental	To determine the workload, physical strain, relationship with management, and worker disability of hotel room cleaning personnel
Housing Options[196]	Nonexperimental	To determine the need for supported living homes for people with HIV/AIDS
James Bay[76]	Nonexperimental	To explore how diabetes is understood by Cree with diabetes, their families, and friends
Madison County[197]	Nonexperimental	To assess residents' concerns about health, health needs, and access to health care in Madison County, NC
Native Hawaiian[188]	Nonexperimental	To understand smoking-related habits, attitudes, concerns, and health problems of Native Hawaiians
PAR CH[198]	Nonexperimental	To conduct a health survey to obtain baseline data on health behaviors
PAR Hmong[219]	Nonexperimental	To plan, develop, and implement a project that allowed Hmong women to share their concerns and work on strategies to address them
Perspectives of Latinas[187]	Nonexperimental	To assess perceptions and attitudes on diabetes risk and impact, physical activity, and factors influencing the participation in physical activity during and after pregnancy
Positively Fit[194]	Nonexperimental	To define appropriate rehabilitation goals for PWAs (people living with AIDS)
Poultry Slaughterhouse[183,184]	Nonexperimental	To characterize the work situation, to identify health problems and their prevalence separately for men and women; to explore associations between health problems and working conditions
South Asian[220]	Nonexperimental	To examine South Asian immigrant women's health promotion issues; to facilitate the creation of emancipatory knowledge and self-understanding; to promote health education and mobilization for culturally relevant action
TAS[186]	Nonexperimental	To assist agricultural worker communities in creating effective solutions to the problem of pesticide exposure
Welcome Home[210,211]	Nonexperimental	To describe factors that support women's successful transition to the community following jail; to continue to develop Welcome Home Ministries as a health-promoting organization

Table 8. Noninterventional CBPR Studies

Study Name	Study Design	Research Objective
WE ACT[213,214]	Nonexperimental	To generate pilot data on temporal and spatial variations in sidewalk concentrations of contaminants at street level and to relate these data to measures of diesel emissions on adjacent streets; to collect data on the levels of diesel exhaust exposure and lung function among Harlem youth

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Table 9. Evidence of community involvement in research*

Study Name and Citations	Select Research Question	Develop Proposal	Have Financial Responsibility	Design Study	Recruit and Retain Subjects
Completed Intervention					
CMCA[113-118]					Yes
East Baltimore[119-122]	Yes				Yes
Health is Gold![123]	Yes	Yes	Yes	Yes	Yes
Sierra Stanford[124,125]	Yes				Yes
HIV Latina[126-130]	Yes			Yes	Yes
Internet Access: A Community-Based Health Initiative[131]				Yes	Yes
Korean Study[132-134,222]	Yes			Yes	Yes
Okanagan[135]				Yes	Yes
Wai'anae[136-138]	Yes	Yes	Yes	Yes	Yes
NY Immunization[139]			Yes		Yes
Stress and Wellness[141-143,223,224]	Yes		Yes	Yes	Yes
Women and HIV Denial[144,145]	Yes		Yes		Yes
Incomplete Interventions or Interventions Not Yet Fully Evaluated					
CAAA[146-148]	Yes	Yes		Yes	Yes
PRAISE[149,150]				Yes	Yes
Seattle Homes Project[151]					Yes
Seattle Vaccines[152]				Yes	Yes
TEAL[153]					Yes
ESVHWP[106,112,155-163]				Yes	Yes
Elderly in Need[92,154]					Yes
Haida Gwaii[77]	Yes		Yes		
Healthy Home[100,164,165]	Yes				Yes
Kahnawake[78,166-169]	Yes	Yes	Yes	Yes	Yes
La Vida[170]	Yes				Yes
ME2[171]					Yes
NRMNC[70]	Yes	Yes	Yes		Yes
PACE[172,173]	Yes	Yes	Yes	Yes	Yes
PINAH[174]				Yes	Yes

* Entries are based on information reported in at least one citation for the study in question.

Table 9. Evidence of community involvement in research (continued)

Participate in Measurement Instruments and Data Collection	Develop, Implement Intervention	Interpret Findings	Disseminate Findings	Apply Findings	Number of Elements of Community Involvement Reported
Yes	Yes	Yes	Yes	Yes	6
Yes	Yes	Yes		Yes	6
	Yes	Yes	Yes	Yes	9
Yes	Yes		Yes		5
Yes	Yes	Yes	Yes		7
	Yes				3
Yes	Yes	Yes	Yes	Yes	8
Yes	Yes		Yes		5
Yes	Yes	Yes	Yes	Yes	10
Yes	Yes				4
Yes	Yes	Yes	Yes	Yes	9
Yes	Yes	Yes			6
Yes	Yes	Yes	Yes		8
Yes	Yes				4
Yes					2
	Yes				3
Yes	Yes	Yes	Yes	Yes	6
Yes	Yes	Yes	Yes	Yes	7
	Yes				2
Yes	Yes		Yes		5
Yes	Yes			Yes	5
Yes	Yes	Yes	Yes	Yes	10
Yes			Yes		4
Yes	Yes	Yes	Yes		5
Yes	Yes	Yes	Yes	Yes	9
Yes	Yes	Yes	Yes		9
Yes	Yes	Yes	Yes		6

Table 9. Evidence of community involvement in research (continued)

Study Name and Citations	Select Research Question	Develop Proposal	Have Financial Responsibility	Design Study	Recruit and Retain Subjects
Preventing Arson[175]					
Survival Guide[176,177]	Yes				Yes
Women and Heart Disease[178]					
Studies Without Planned/Evaluated Interventions					
AABLH[179]	Yes	Yes		Yes	Yes
Hospice Access[180]					
Oregon Migrants[181,182]			Yes		Yes
Aboriginal[192,193]					
Bingham[195]					Yes
Chinese Elderly[199]					Yes
CHEP[200-202]	Yes	Yes	Yes	Yes	Yes
Controlling Pesticides[189]					Yes
Diabetes in East Harlem[190]	Yes	Yes		Yes	Yes
Disability Community[191]	Yes	Yes	Yes	Yes	Yes
EJS[215,216]	Yes			Yes	Yes
ECFA[203-208,225]				Yes	Yes
EBFP[217]	Yes		Yes	Yes	Yes
Glades[212]			Yes		
The Harlem Birth Right Project[209]				Yes	Yes
Healthy Neighborhoods[69,218]					Yes
HERE[185]	Yes	Yes	Yes	Yes	Yes
Housing options[196]				Yes	Yes
James Bay[76]	Yes		Yes		Yes
Madison County[197]				Yes	Yes
Native Hawaiian[188]				Yes	Yes
PAR CH[198]	Yes	Yes		Yes	Yes
PAR Hmong[219]	Yes				Yes
Perspectives of Latinas[187]					
Positively Fit[194]			Yes		Yes
Poultry Slaughterhouse[183,184]				Yes	Yes

Table 9. Evidence of community involvement in research (continued)

Participate in Measurement Instruments and Data Collection	Develop, Implement Intervention	Interpret Findings	Disseminate Findings	Apply Findings	Number of Elements of Community Involvement Reported
	Yes				1
Yes	Yes			Yes	5
Yes	Yes	Yes	Yes		4
		Yes	Yes		6
Yes			Yes		2
Yes			Yes	Yes	5
Yes		Yes	Yes		3
Yes			Yes	Yes	4
Yes					2
Yes	Yes	Yes	Yes	Yes	10
Yes		Yes			3
Yes		Yes	Yes	Yes	8
Yes	Yes	Yes	Yes		9
Yes		Yes	Yes	Yes	7
Yes		Yes	Yes	Yes	6
Yes					5
				Yes	2
Yes	Yes	Yes	Yes		6
Yes	Yes	Yes	Yes	Yes	6
Yes	Yes	Yes	Yes	Yes	10
Yes		Yes	Yes		5
Yes		Yes	Yes	Yes	7
Yes			Yes	Yes	5
Yes	Yes	Yes	Yes	Yes	7
Yes		Yes		Yes	7
	Yes				3
		Yes		Yes	2
Yes	Yes	Yes			5
Yes		Yes	Yes	Yes	6

Table 9. Evidence of community involvement in research (continued)

Study Name and Citations	Select Research Question	Develop Proposal	Have Financial Responsibility	Design Study	Recruit and Retain Subjects
South Asian[220]			Yes		
TAS[186]	Yes	Yes			Yes
Welcome Home[210,211]					
WE ACT[213,214]	Yes	Yes	Yes		
Total	28	14	19	28	50

Table 9. Evidence of community involvement in research (continued)

Participate in Measurement Instruments and Data Collection	Develop, Implement Intervention	Interpret Findings	Disseminate Findings	Apply Findings	Number of Elements of Community Involvement Reported
Yes	Yes	Yes	Yes	Yes	6
Yes		Yes	Yes		6
	Yes	Yes	Yes		3
Yes		Yes	Yes		6
50	38	39	41	28	

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.

Significance
❑ Reflects a synthesis of the latest epidemiological and clinical literature regarding the health problem identified and the existing barriers to change. ❑ Presents a clear and up-to-date understanding of CBPR literature and principles. ❑ Reflects a realistic understanding of the potential limitations of CBPR (such as significant time requirements subjectivity associated with community data collectors). ❑ 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. ❑ 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.
Innovation
❑ 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. ❑ Builds on identified community strengths, such as existing organizations and networks, cultural beliefs, and political will. ❑ 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. ❑ Includes embedded substudies designed to assess the degree to which CBPR methods enhance or diminish research quality.
Approach
❑ 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. ❑ 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). ❑ 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). ❑ 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). ❑ Reflects a blend of flexibility and rigor in implementing sound research methods that respect participants' interests. ❑ Measures include socioeconomic determinants of health, and interventions reflect an understanding of these influences. ❑ Intervention studies include cost-effectiveness analysis and feasibility assessment to determine long-term sustainability within the research community and/or other groups. ❑ 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. ❑ Includes process measures to document and understand the partnership dynamics and the feasibility and acceptability of intervention, measurement, and data collection approaches.

Exhibit 2. CBPR reviewer checklist (continued)

Translation (when relevant)
❑ 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). ❑ 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). ❑ Includes plans to assess longer-term sustainability of interventions evaluated as part of the study.
Investigators
❑ Includes community members on the list of key personnel and provides biographical information about leaderships' roles and responsibilities in the community. ❑ Ensures that biosketches and descriptions of academic partners reflect prior collaborative research involvement with communities (beyond simply research "in" the community). ❑ Includes, in the preliminary studies section, relevant work of the academic as well as community partners.
Environment
❑ 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). ❑ Describes the political environment as either a support or challenge related to sensitive research topics such as HIV-AIDS, smoking, or domestic violence. ❑ 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).
Budget and Timeline
❑ Reflects the resources and time needed to develop or enhance community partnerships. ❑ 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). ❑ 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.

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.ccph.info/Others
  - Israel Schulz, Parker, 1998*
  - Viswanathan, Ammerman, Eng, forthcoming†
- 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.

† 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.

Exhibit 3. CBPR requests for applications and peer review (continued)

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

Chapter 4. Discussion

Defining CBPR

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

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

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 Chapter 3) 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.

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

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

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Listing of Excluded Studies

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Notes: Insufficient Information

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