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, 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. This allowed us to target our literature search and helped us to identify appropriate databases and other resources for this systematic review. In particular, we presented draft key questions to the expert meeting attendees. Based

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

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 (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 298 articles for complete review and excluded 113 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 107].

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. Furthermore, 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

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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 the 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

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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 the scores, discussing any discrepancies until these were resolved, and assigning 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

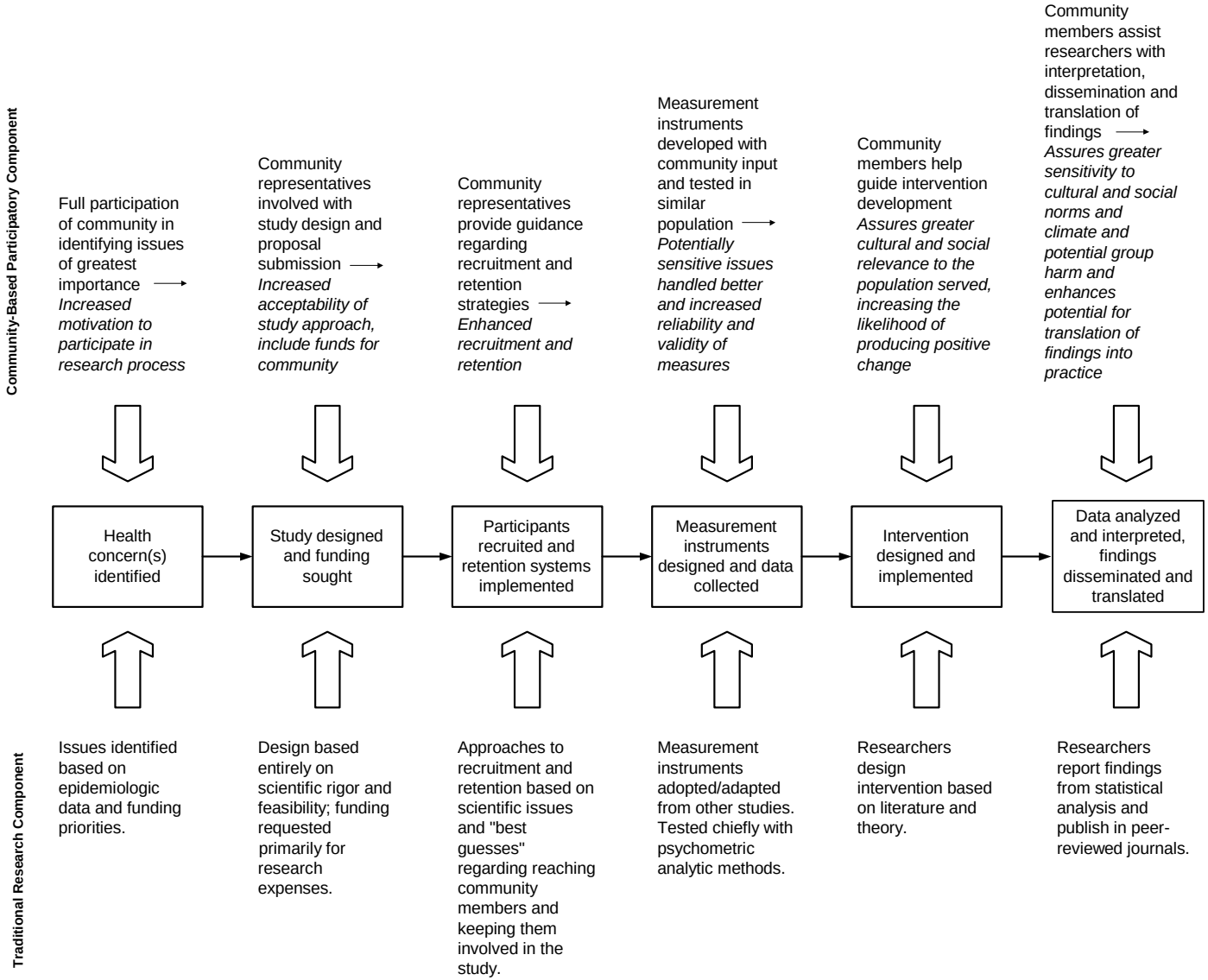

Table 1. Critical elements in community-based participatory research

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