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 concerns 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. KQs 2 and 3 focuses 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,

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.

KQs 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 KQs 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 funding applicants (proposal writers), reviewers, and agencies toward submitting and funding the best possible CBPR. To this end, we used the findings for KQs 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. This deliberately short, workable 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. We emphasize the essential elements of community participation, the essential elements of research, and best practices for 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 (nontechnical) 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, the 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 inevitably 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, 4 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, Stress and Wellness, and Wai'anae), 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, 4 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]); 1 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 noninterventional studies, 27 were nonexperimental and primarily exploratory in nature. The other three 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 (16 of 30) were predominantly concerned with understanding the problem at hand. 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 (62 percent) used qualitative methods either alone, or in combination with quantitative methods. 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 six studies, the investigators combined qualitative and quantitative methods (CHEP, ECFA, HERE, Hospice Access, TAS, and Harlem Birth Right). Eleven studies (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 of 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 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 analyses will typically 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. 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 three of the four 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 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; however, such bias was not measured directly,.

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 (10 of 30) reported that communities were engaged in designing interventions for the community based on the results.

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 KQs 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 KQs 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 (p. 15) provides a detailed framework of CBPR principles and their benefits. This information is also available on the RTI Web site (http://www.rti.org) in the document "CBPR Reviewer and Applicant Guidelines," (CBPR Exhibit 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 suggested 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 online (at http://www.rti.org) as CBPR 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,"[221] which appraises the extent to which proposals or projects align with principles of participatory research.

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. However, these guidelines are our recommendations and have not been formally adopted by AHRQ or other components of HHS.

The "CBPR Reviewer Checklist" (Exhibit 2) goes one step further, adding to these suggested 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 Community-based Participatory Research 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 Community-based Participatory Research 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. Community-based Participatory Research 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. Community-based Participatory Research 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 Community-based Participatory Research 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 Community-based Participatory Research studies (continued)

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 Community-based Participatory Research studies (continued)

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* [*Read across for full entry*]

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) [*Read across for full entry*]

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) [*Read across for full entry*]

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	