

FINAL Report and White Paper
**Assessment of Existing Linkages with Local Communities among Potential
Research Sites for the National Children's Study**

Prepared for:

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Final Report

Introduction

This paper was prepared to assist the planners of the National Children's Study (NCS) as they assess possible study design options and consider the role of the community in this initiative. The consensus among the planners is to involve the community in the conduct of the study. What is not yet clear is how—to what level and at what capacity—the community will be involved. To answer those questions, the NCS planners will need to understand potential strengths and weaknesses of a study design that depends on community involvement and the level and type of support that local study sites would need to be able to work with the communities.

In response to the planner's need to learn more about community-based research (CBR), RTI International (RTI) conducted a literature review and searched the Internet for information on the status of community-based research in the United States today. In this report, we identify the methods used to gather the information to develop the white paper. We are attaching the bibliography of relevant material in Appendix A and the references used in the white paper in Appendix B.

Method

We searched the following databases for English language records from 1994 to present: the library collections, e-journals and databases from NC State University, UNC-Chapel Hill and Duke (for the locally held items), PubMed, PsycINFO, and Sociological Abstracts and the Online Computer Library Center (OCLC) which is a worldwide interlibrary loan networking system. We included peer-reviewed published articles in the English language. We excluded editorials, letters, and commentaries and articles that did not report information related to the questions and concerns identified by the planners. We included any studies/projects that included at least one community as a partner or collaborator. We used the following search strategy:

Keywords used for literature search:

- Community participatory research
- Community-based research
- Community-based participatory research
- Participatory research
- Community research
- Community involvement
- Community involvement & research
- Community engagement
- Community engagement & research

- Community retention in research.

All of the above words were combined with “in [state name]” and then “& [state name]” for the search. Additionally, we substituted the acronym for the type of research, e.g., CBPR for community-based participatory research, CBR for community-based research.

Search Engines

- Google
- Microsoft Internet Explorer
- StaffNet
- World Wide Web Resources for Social Workers
- EBSCO

Literature Search Results

We identified a total of 119 abstracts for review. Of those, we retained and pulled 23 articles for complete review.

Appendix A – Bibliography

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Executive Summary

The planners of the National Children's Study (NCS) clearly want to involve the community in the conduct of the study yet questions remain about what type and level of involvement is most appropriate and beneficial. To answer those questions, the NCS planners need to understand the strengths and weaknesses of a study design that depends on community involvement and its impact on study design.

In response to the planner's need to learn more about community-based research (CBR), RTI International (RTI) conducted a literature search and searched the Internet for information on the status of community-based research in the United States today. This paper summarizes the results of our search and provides recommendations to the NCS planners on incorporating CBR in their study design.

In our search, we found that some communities have become quite accomplished in their collaborations with research studies as a result of their experience with this approach to research. However, not all CBR studies are capable of functioning at this level. Researchers and communities must consider the level to which they want to involve communities in studies that impact their lives. This requires taking a hard look at the realities of each situation and assessing their ability to be involved.

Our search results confirmed that community-based research is time and resource intensive, and that the target population participation and retention rates increase when the community buys in to a study. This is particularly true for special populations. We also found that there is a growing network of partners --- communities and researchers who have committed to this approach and are building supportive tools to sustain the mission of improving the health of their communities.

Community-Based Research and Public Health

1.1 Introduction

This paper was prepared to assist the planners of the National Children's Study (NCS) as they assess possible study design options and consider the role of the community in this initiative. The consensus among the planners is to involve the community in the conduct of the study. What is not yet clear is how—to what level and at what capacity—the community will be involved. To answer those questions, the NCS planners will need to understand potential strengths and weaknesses of a study design that depends on community involvement and the level and type of support that local study sites would need to be able to work with the communities.

In response to the planners' need to learn more about community-based research (CBR), RTI International (RTI) conducted a literature search and searched the Internet for information on the status of community-based research in the United States today. This white paper summarizes our findings. In this report, we identify states that have the capacity to conduct CBR; provide a list of current and past CBR projects, noting the lessons learned from the partnerships and various study designs; analyze the various ways communities have been involved; and identify capacity-building tools and techniques. We also provide recommendations that will allow the planners to decide the optimum manner in which to involve the community in the conduct of the NCS.

We have divided the paper into six sections. The report begins with an overview of CBR, including background and definitions and an examination of the distinction between “doing” research on the community and community-based research. Section 2, a “how-to” section on capacity building for a CBR study, covers the basics of building or enhancing the foundation needed to implement and sustain a CBR study. Section 3 presents the benefits and challenges to conducting community-based research. Conclusions based on our examination of the topic in relation to the questions raised by the NCS planners are presented in Section 4, and our recommendations are provided in Section 5. A glossary of terms is provided in **Appendix A**. Additionally, we provide CBR resources, references, results of our literature search, and tools in **Appendices B through D**. **Appendix E** lists the CBR projects we identified during this assignment by state, with contact information and a brief summary of the initiative. Also included in this appendix is a list of noninterventional CBR studies with a detailed study reference.

1.2 Background and Definitions of Public Health and Community-Based Research

The following definition of public health put forth by Winslow in 1949 is still referenced because it so aptly shows the codependency of the practice of public health and the involvement of the community:

Public health is the science and art of preventing disease, prolonging life, and promoting physical and mental health through organized community efforts for the sanitation of the environment, the control of community infections, the education of the individual in the principles of personal hygiene, the

organization of medical and nursing services for the early diagnosis and treatment of disease, and the development of the social machinery which will ensure to every individual in the community a standard of living adequate for the maintenance of health.

Blumenthal and Yancey (2004) hold that the connection between public health and community-based research is so strong that “an understanding of the function and history of public health is needed in order to understand community based research.” Community-based research is not a new concept in the field of public health. The concept of involving the community in the prevention of illness was introduced in 1880 when New York City established a Division of Child Hygiene in the New York Health Department. This Division went on to demonstrate that public health nurses could reduce infant mortality through home visits and teaching (State of Missouri, 2001). Improving the public’s health by teaching the principles of hygiene and sanitation to those who stood to benefit became one of the mainstays of public health nursing as it evolved. Lillian Wald was the leading figure in the development of the profession of public health nursing (Nursingworld, 2001) and thus became one of the pioneers of public health education.

1.3 Conducting Research in the Community Versus Conducting Community-Based Research

The major difference between community-based research and traditional research is how the community is perceived and incorporated into the study. The traditional research model presumes that the “experts” will study the subjects. That is, the experts (researchers, funding sources, and policy makers) will identify the research agenda, collect the data, analyze the data, make public policy, and publish the data. On the other hand, community-based research presumes that both parties, the researchers and the community, bring value to the research table. To translate this collaborative spirit into an actual research project requires that certain considerations be addressed. These considerations, which are unique to CBR, “include the principles that govern relationships between the collaborators, and the principles of cultural competence that prepare researchers to create the community partnerships needed to conduct community based research” (Blumenthal et al., 2004).

Community-based research in public health is a partnership approach to research, which equitably involves community members, community organization representatives, and researchers in all aspects of the research process to enhance understanding of a given phenomenon and to integrate the knowledge gained with action to improve the health and well-being of community members (Israel et al., 1998).

Viswanathan et al. (2004) advanced the discussion of the definition of community-based participatory research (CBPR). She and her colleagues propose that CBPR is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being by taking action, including social change. They point out that this definition by itself does not completely convey the critical philosophical or practical aspect of CBPR. Therefore, they suggest that the concept should be extended to emphasize three main ideas:

- CBPR is about “co-learning” by both researchers and community collaborators and “mutual transfer” of expertise and insights into the issues of concern and, within those, the issues that can be studied with CBPR methods.

- CBPR is about “sharing in decision making.”
- CBPR is about “mutual ownership” of the processes and products of the research enterprise.

To ensure better health of communities in the twenty-first century, researchers and epidemiologists in the field of public health must take a proactive stance and develop creative yet practical ways to promote and support multiple partnerships throughout the community. This concept can be advanced by

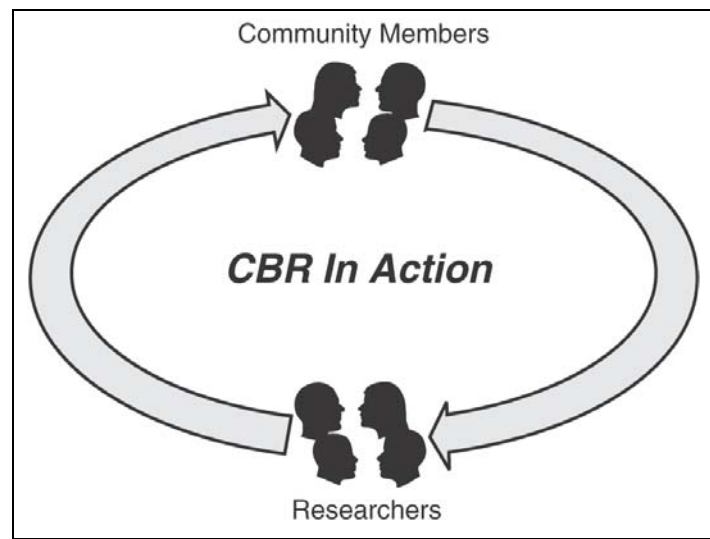
- Implementing a population health approach that considers the impact of the environment on the population
- Promoting and supporting nontraditional partnerships for community health
- Insisting that evidence-based research drive public health decisions and recommendations
- Facilitating communication between the community and other health partners
- Empowering the community to better manage their health outcomes.

Leung and colleagues (2003) suggest “At this critical juncture in its history, epidemiology may benefit from further incorporating CBR, increasing the field’s ability to study and understand complex community health problems, insure the policy and practice relevance of findings, and assist in using those findings to help promote structural changes that can improve health and prevent disease.”

Building a Community-Based Research Model

Community-based participatory research involves a collaborative partnership in a cyclical, iterative process in which defined communities play a lead role in identifying the community strengths and resources; selecting priority issues to address; collecting, interpreting, and translating research findings in ways that will benefit the community; and emphasizing the reciprocal transfer of knowledge, skills, capacity, and power. The focus of the partnership is driven by issues and concerns identified by members of the community (Israel et al., 2000).

The literature is exhaustive on the different forms or styles of community-based research. There is community-based research, community participatory research, participatory action research, and community involvement, to name a few schools of thought. Despite the nuances in the definitions of CBR, there is a consensus that the strategy of involving the community in research is the most effective way of ensuring the greatest level of success for any project or program that is intended to impact the community. There is also a consistent theme in the literature regarding when to involve the community. The recommendation is to involve the community early, as often as appropriate (depending on the design of the study), and throughout the study. This includes involving them in interpreting the findings and in analyzing, evaluating, and publishing the data.



2.1 Becoming Acquainted with the Community

When looking at best practices, the literature shows that most successful CBR projects invested time in the preliminary stages of the project to develop relationship with the defined community. That is, the planners of the project were thoughtful and deliberate in their approach to the community. Understanding the general concerns of the public about researchers who have traditionally entered the community to “do” research on the community, they took special measures to make certain that they were acquainted with the community before soliciting cooperation from the community. Some of the special measures and community organizational tools used during the preliminary stages of these studies are described in this section.

Becoming acquainted with the community entails having a presence in the community. In many cases the researchers and/or partners may not actually be a part or member of the defined community, but they may be recognized by the community as being affiliated with them as a result of their roles in the community (e.g., health professionals, teachers, community social agency workers). Then the question becomes a matter of quality of affiliation. That is, are the partners perceived by the community as adding value to their community? The more

value perceived by the community, the easier the task of beginning the dialogue with the community regarding their role in the research. For example, a medical facility or health practitioner who has a record of serving the community well is in a strong position for partnering with the study, whereas a facility or practitioner who has a reputation for under delivering service to the community does not make for a credible partner for the study team. In fact, if the study team is not able to make these distinctions in a community, it shows the lack of familiarity with the community and indicates that more attention is required for the “acquaintance process.”

The next step for the research team is to identify which members of the defined community should be approached to begin formal communication concerning the research project. Using the information from members of the team who are acquainted with the identified community, the researchers should determine who the key representatives are in the community and approach them for assistance with the project. These people will form the basis for the partnerships needed for the study. Sources of potential partners for the NCS include

- Medical and health facilities
- Health providers and workers
- Social service agencies
- Community organizations
- Public and private schools
- Colleges and universities
- Research institutions
- Local and state governments
- Civic associations
- Fraternities and sororities
- Volunteer organizations
- Businesses
- Departments of public transportation
- Places of worship
- U.S. military (civilian and dependent services branch)
- Local and national media outlets.

Because demographic and geographic considerations must be made in deference to the community, a briefing session should be arranged as soon as possible to present the research plans to the potential partners. Depending on the site, the session may be as small as a few key people or large enough to fill a town hall. The objective of the session is to meet and exchange information with the community representatives. The exchange should, at the least, include the status of the study, immediate and long-range planning goals, mention of the possible partnership roles for the community, and a tool (perhaps a survey to be completed and turned in at the end of the session) to capture the concerns of the community. The session should conclude with an announcement of a date and place for the next meeting and preferably with a tentative agenda.

2.2 Establishing Trust

When developing a CBR project, there is a need to build trust despite organizational boundaries and organizational cultures and to make a paradigm shift in the locus of power and control. The traditional research paradigm for working with communities is that the experts—the researchers and policy makers—know the best way to “handle” the research, yet they often forget that the research is occurring in the dynamic community rather than in a controlled laboratory. The shift in thinking must occur on both sides of the table. That is, the community must also change how it has functioned in similar situations in the past. The community must understand and accept its responsibility to the study by, for example, attending scheduled meetings, providing input and feedback as needed, and upholding any commitments made to the study team. Some CBR studies go as far as developing and signing Memorandums of

Understanding (MOUs) or Partnership Agreements between the research team and the community. An example of each type of commitment can be found in **Appendix B**.

Another productive way to build a collaborative relationship is to take an inventory of the assets and resources brought to the table by all of the partners. This is best accomplished at a special meeting or session where participants have been given the opportunity to prepare for the group exercise of sharing the inventories. Once the inventory is made and discussed, the next step is to match those assets and resources to the needs of the study. At this point roles and tasks also become apparent, assignments can be made, and resources shared. For example, community representatives may find that their organization may be more helpful to the study by serving as a host to the study team instead of serving on an advisory board. This exercise should be revisited at critical points in the study to maintain the groups' integrity.

2.3 Identifying Needs and Resources

Understanding the environment in which the study data will be collected is critical in designing a protocol that will succeed in the community. Perhaps most important, it is an empowering exercise for the community to focus on assets and strengths—emphasizing what the community does have, not what it does not have. This approach places value on things that the community may have begun to devalue, overlook, or take for granted. In order to gain this information, an inventory of the assets and resources must be conducted.

2.3.1 Defining a Community Asset

A community asset, or community resource, is anything that can be used to improve the quality of community life. It could be a person, a physical structure or place, or a business in the community. Identifying community assets is a critical step in the study process. The study team will need to understand the available resources as plans are developed for the study; and community residents can be empowered as they identify and mobilize community assets. Everyone in the community benefits from this exercise. Some of the tools and methods that can be used to help with this task are described in Section 5 and sources are listed in **Appendix B**.

2.3.2 The Concerns Report Method

The Concerns Report Method (CRM), a popular method for assessing community needs and resources, is often used when groups place a high value on input from members of the community. The CRM uses either a Concerns Survey or public meetings to develop a report on the major health-related strengths and problems of local communities from the perspective of local citizens. The CRM goes beyond the usual needs assessment survey and becomes an organizing tool. A working group of community representatives designs the survey and then collects data from the community that will identify and prioritize the concerns in the community. Then public meetings are held for the community to mobilize around the identified concerns. The CRM offers valuable ideas for addressing the needs of the defined community.

2.3.3 When Should Needs and Assets be Identified?

Identifying needs and assets can be helpful to the study at almost any point in the process. For example, given the number of protocols to go into the field for the NCS, identifying needs and assets at a specific site can help the planners decide which of the protocols should be implemented first and where. The process of identifying resources and needs should be done on an ongoing basis throughout the NCS. It will be just as important to make certain that the study is on track in the middle of the study as it is in the initial and ending stages.

2.4 Communication

The adage “no news is good news” does not hold true while working in the community. In fact, to decrease or cease regular communication with the community can bring unnecessary burdens to the study. Gorelick and colleagues (1996) found that exclusion of community leaders in the planning phase may lead to rejection and failure of the health initiative once it is launched. This is a sound reason to begin some form of communication as soon as possible about the study with the communities to be included in the NCS. The community will have questions that they will want answered regarding the preparation for the study. A good starting point is to frame the communication around the key principles or characteristics of community-based research (Israel et al., 1998).

2.4.1 Principles of Community-Based Research

It is important to note that, although the principles of community-based research remain the same, the application is evolutionary. That is, these principles are on a continuum and will operate at the level of capacity of the study design and partners. For example, equitable participation and shared control over all phases of the research process (Cornwall et al., 1996; Green et al., 1995) is the goal. However, the actual amount of shared control will depend on the circumstances of the study, the purpose, and the participants involved. Based on the assumption that the researchers will build an appropriate relationship with the community, Israel et al. (1998) state that such a study will have the following attributes:

- **Recognizes community as a unit of identity.** A community may be a geographic entity but, alternatively, may be defined by some other commonality among members such as ethnicity or occupation.
- **Builds on strengths and resources within the community.** Public health workers and researchers have often described communities by their needs and problems, but a more contemporary approach to community health needs assessment calls for an inventory of the community’s assets (e.g., businesses, churches, schools, organizations, and agencies) as well (Sharpe et al., 2000).
- **Facilitates collaborative partnerships in all phases of the research.** Communities should share control over all phases of the research process: problem definition, data collection, interpretation of the results, and application of the results.
- **Integrates knowledge and action for the mutual benefit of all partners.** Results of community-based research should not only be added to the broad base of knowledge of community health, but should be integrated into local efforts at community change.
- **Promotes a co-learning and empowering process that attends to social inequalities.** Researchers and community members learn from each other. Moreover, researchers recognize the inherent inequality between themselves and community members and attempt to address this factor by sharing information, decision-making power, resources, and support.
- **Involves a cyclical and iterative process.** This cycle proceeds from partnership development and maintenance through community assessment, problem identification, development of research methodology, data collection, analysis, and interpretation, through dissemination of results, determination of action and policy implications, taking action, and establishing mechanisms for sustainability. By implication, the process then starts over.

- **Addresses health from both positive and ecological perspectives.** This speaks to a holistic approach to investigating health outcomes in the community.
- **Disseminates findings and knowledge gained to all partners.** Results of the research must be shared with community partners in understandable language, and participants should be consulted prior to submission of manuscripts for publication, acknowledging the contributions of participants and developing co-authored publications when appropriate.

2.5 Types of Partnerships

Beyond the collective definitions of community that researchers and organizers can apply, an individual also has her or his own sense of community membership. The presence or absence of a sense of membership in a community may vary over time and is likely to influence participation in community activities. This variation is affected by a number of factors. For example, persons at one time may feel an emotional, cultural, or experiential tie to one community; at another time, they might believe they have a contribution to make within a different group. At yet another time, they may see membership in a third distinct community as a way to meet their own individual needs (Chavis et al., 1990). Of course, they may also have a sense of belonging to more than one community at the same time. Before beginning an engagement effort, it is important to understand that all these potential variations and perspectives may exist and influence the work within a given community.

2.5.1 Principles of Partnerships

The body of CBR work provides evidence that there is agreement about the importance of communication, inclusion, and expectation for diversity in the partnerships. There is also concurrence with the profile of key community representatives or partners and their roles on the study. The literature indicates that potential partners should be approached as early in the planning process as possible. The types of partners required for a project will be driven by the type of study and community. No matter what form of partnership is decided upon, experienced CBR participants seem to agree on basic principles for a successful partnership. One of the vanguard organizations in CBR, Community-Campus Partnerships for Health (CCPH), has published the following guiding principles for sustaining working relationships between academic institutions and communities (CCPH, 1997):

- Partners must agree on missions, goals, and outcomes.
- Partners should have mutual trust, respect, and commitment.
- Partnerships need to build on identified strengths and assets. Instead of approaching a community-based partnership solely by itemizing all of the problems that the community faces, the partners should also identify their strengths and assets.
- Good partnerships should have clear communication among partners and transparency in the decision-making process.
- Partnerships evolve using feedback to, among, and from all partners.
- Roles, norms, and processes for the partnerships should evolve from the input and agreement of all partners. Partnerships need a governance structure that establishes a common understanding of how to proceed.
- Successful partnerships have relationships with local leaders and funding agencies.

- Effective partnerships use existing structures, such as schools and worksites, to incorporate solutions into their mission.

2.6 Levels of Community Engagement

As there are various partners, so are there varying levels of involvement in community-based research. Four levels of involvement were identified by Hatch et al. (1993). The first level of involvement is usually in an advisory capacity, such as an advisory board. The literature shows that the advisory level can be either a legitimate role or a counterfeit role. The integrity of the advisory position is dependent on the understanding and degree of collaborative intent of the researchers and the advisors (partners). Blumenthal and Yancey (2004) offer that, “at the first level, the persons consulted by the researchers are at the periphery of the community, often working for human service agencies and living outside the community. In this model community residents are unaware of the purpose of the research and have no influence on its design.”

Hatch et al. (1993) found that, at the second level, the community leaders recruited from organizations, churches, and other institutions in the community are consulted as advisors to the planners on the research design. At this level of involvement there is community participation, albeit passive, since the researchers retain control over the study.

During the third level, Hatch and colleagues found that community leaders are asked not only for endorsement of the project, but for guidance in hiring community residents as interviewers, outreach workers, and so forth. They point out that this model is “community based but not community involved, since community members do not contribute to the design of the research nor do they have a significant role in interpreting findings.”

The fourth level, according to Blumenthal and colleagues (2004), both involves and empowers the community. The community representatives are equal participants in defining the research agenda, identifying the problem to be studied, analyzing its contributory factors, and proposing possible solutions. The community “negotiates, as a collaborator, the goals of the study, the conduct of the study, and the analysis and use of the study findings.”

At level four, there are likely to be conflicts and differences between the researchers and the community. The challenge to the researchers is to negotiate these differences and to build a trusting relationship with the community rather than to search for another more compliant venue in which to implement their plans. A trusting relationship between community and researcher is the most difficult to attain but one that is most conducive to conducting effective and ethical community-based research (Blumenthal et al., 2004). It is important to note that at level four “Epidemiologists would not be required to surrender rigor, but they would be required to share power!” (Schwab and Syme, 1997). This fact would hold true throughout the levels of community involvement.

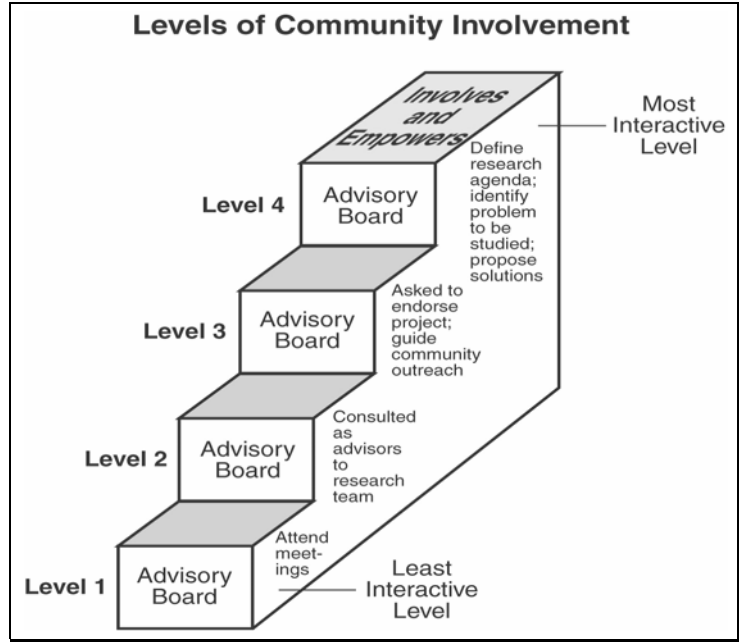
The process of engaging the community also has tenets and guidelines. The Mobilizing for Action through Planning and Partnership (MAPP) program, which is supported by the National Association of County Health Officials (NACCHO) and the Centers for Disease Control and Prevention (CDC), has found the following principles and guidelines to be effective when working with communities. These principles may be useful to the planners of the NCS as the investigators begin to engage the community in the study.

Principles:

- People should have a say in the decisions that affect their lives.
- A public participation process, by definition, belongs to all the stakeholders, including future generations.

Guidelines:

- The public participation process must provide participants with the information they need to participate in a meaningful way.
- The public participation process should address the interests and meet the process needs (time, venue, etc.) of the largest possible number of participants.
- The public participation process should seek out and facilitate the involvement of all stakeholders.
- The public participation process should communicate to all stakeholders how input affects the decisions made.



2.7 The Process of Community-Based Research

The process, the “how-to-do-it” of community-based research, is rooted in the basics of community organizing. The best models for guidance in developing relationships with communities are not research models, but rather community health planning programs. Programs such as the World Health Organization’s “Healthy Communities” Program (Hancock, 1993) and CDC’s “Planned Approach to Community Health” (PATCH) (Goodman et al., 1993) are excellent examples. Braithwaite et al. (1989) describe a model of “community organization and development for health promotion” that borrows from the “empowerment education” approach of Paulo Friere (1968). They list seven principles in the model as guidance to health educators or community organizers:

1. **Learning the community layout.** Entry to the community should be preceded by a study of community geography, health status measures, etc.
2. **Learning the community ecology.** Identify places where people congregate and meet community leaders and “gatekeepers” and learn their relationship to one another.
3. **Community entry process.** The process must be negotiated with gatekeepers, and the community organizer must be “validated” by the formal and informal community networks.
4. **Building credibility.** It is important to speak truth to the community. That is, do not make promises and/or commitments that cannot be kept. Therefore make no commitments to matters that are beyond the study team’s control.

5. **Development of a community coalition board.** This board should be consumer-dominated (at least 60%) but also include academic, agency, and organizational representatives as well as elected officials.
6. **Conducting a community needs assessment.** Identify those health issues felt by community residents to be most important by surveying or other similar methods.
7. **Planning the research project.** Early in the planning stage, begin to think about how the study team will provide feedback on the results of the project to the community.

These are tried and true principles that build relationships, that is, what must occur first before any research can proceed. When the lines of communication are open, issues such as mistrust and fears of exploitation can be dispelled. People can then get on with the business of building healthy communities.

2.8 Special Cultural Considerations

The landscape in which CBR is conducted is dynamic. The ever-changing American population requires researchers to be aware of the changes in communities and to modify and develop appropriate methodologies to address diverse groups. Following are some examples of the cultural challenges researchers face in community-based research.

2.8.1 The Hispanic Community

Mexicans, Chicanos, Puerto Ricans, Cubans, Dominicans, Colombians, and Salvadorians, all of whom are classified as Latino or Hispanic, constitute the fastest growing minority population in the United States. Approximately 32.4 million Hispanics currently live in the United States, and it is estimated that, by the year 2005, Hispanics will be the largest U.S. minority population. Moreover, between 2000 and 2050, Hispanics will account for the majority of the nation's population growth (U.S. Census, 2000).

One of the most basic yet powerful approaches to understanding this population is to understand that the terms Latino and Hispanic are extremely broad and include different cultural values, beliefs, and religious backgrounds. Cruz et al. (2004) explain that the differences among Hispanics are influenced by

- Education
- Socioeconomic status
- Immigration status
- Age
- Length of time in the United States
- Degree to which they have adopted Anglo behavior and values
- Rural versus urban residence
- Country of origin, or of ancestral origin.

With the acceptance of this fact researchers should design studies that incorporate this degree of cultural intelligence. Rather than base the study design on a faulty premise (either consciously or not) that all Hispanics are the same and therefore we only need to hire some Hispanic speaking data collectors and translate the study materials into Spanish in order to address this population, more culturally appropriate preparations can be made. For example, the researchers should gather specific information on the study population and then adjust the staffing pattern and study materials to reflect the Hispanic community they intend to work with on the study.

2.8.4 The Southeast Asian Community

The Asian community is a diverse one. Although classified as Asian in the United States, Chinese, Thai, Vietnamese, Cambodian, Laotian, and various other Asian ethnic groups have widely varying language, food, values, and customs. Cruz et al. (2004) report that the greatest similarity among Southeast Asians is the reason they came to the United States—they are refugees from the wars and violence that have devastated their homelands.

Research is not a new concept to them. The antibiotic lincomycin was used freely in Vietnam, Thailand, and other Southeast Asian countries. When the immigrants came to the United States, their doctors told them that lincomycin had bad side effects and is not used here. Those who had taken it felt disappointed and duped that they had been used as guinea pigs (Cruz et al., 2004).

Southeast Asians are usually willing research participants when they think that the research will help others. Neufeld and colleagues (2001) found there was no mystery to the presentation that would engage them. This team of researchers found that providing the participants with basic information such as the reason for the research in Although this group is generally receptive to research, there are limits. Southeast Asians are a deeply private people who guard their family secrets carefully. Questions concerning family health history are especially taboo. Thus, successful community-based researchers must show cultural competence, developing sensitive questions and using skilled translators to ask them (McKelvey et al., 2002).

Another important observation shared by Cruz et al. (2004) is that Southeast Asian people take offense to the term “minority.” In their country “minorities” are indigenous tribes who live an isolated life in the mountains and who are treated badly by the government. Using the term in this country makes them uncomfortable, as Southeast Asians are proud of their heritage. They want to be in mainstream society while maintaining their heritage.

2.8.5 The Black or African American Community

As in the other communities described earlier, this community is not analogous. In fact there remains disagreement within the community as to how they would like to be identified. African American, African hyphenated American, Black American or Black are the most common self-descriptors, and thus should be acceptable for researchers to use. However, it is wise to simply ask the local group of interest for their preference, then use that term.

Many people gather information about Black Americans either from the mass media, e.g., newspapers, television, radio, and magazines, or from research studies. These sources add to the misconception that this is an analogous community, when in fact there are as many differences within this community as there are in other ethnic groups. The differences among Blacks are influenced by

- Education
- Socioeconomic status
- Degree to which they have adopted the majority behavior and values
- Rural versus urban residence
- State, city, town, neighborhood residence
- Ancestral origin (and whether they are aware of this information)
- Age.

When the individual's relationship with various institutions (e.g. hospitals, schools, penal systems, public services, and the government) is added to these distinctions, it is clear that

broad generalities about Black Americans may not be useful. Instead, it is advisable to use deliberate community-relationship-building skills with this community such as listening and dialogue.

It would also be helpful to the NCS research team to understand that, although this is a matriarchal society and men may be absent from the households, this community still highly values their men. This is an important concept to embrace when planning a study that will particularly involve women and children. In many cases, if the study team can convince and earn the trust of the woman, the entire family will cooperate.

2.8.6 Native Americans

Prior to conducting a research project involving the Native American community, we need to learn more about them. Demographic information is available from Federal statistical databases, and the Internet is an excellent source of information on different tribes and/or nations. However, research teams will have to research the specific community first and then adapt the protocol design to match the needs and reality of that community.

2.8.7 Cultural Competence

An operational definition of cultural competence in research is the ability of the researcher to adapt the protocol to meet the environmental needs of the identified community. An example of this postulate is demonstrated in how RTI has used incentives and acknowledgments on field studies with certain populations. When designing a protocol for an inner-city community we realized that offering the incentive in the form of an out-of-state corporate check would not meet our goals, but would rather pose a new set of problems for the respondents. For most of the people in this community, the only method of cashing a check was through a check-cashing establishment that charged a fee, so we settled on a more culturally appropriate form of incentive. We negotiated with a city-wide retailer to offer prepaid gift cards. As expected, this level of attention to the community allowed us to meet our goals.

Another aspect of cultural competency when working with Black American communities is sensitivity to the instances of historical exploitation and abuse from medical and public health research conducted in black communities. Despite pressing health needs, this community is distrustful of research studies and requires a research team to allay their concerns before they will commit to participating in a study.

The point of “culturally competent research [is that it] strengthens the effectiveness of researchers, health care providers, and health service systems by providing them with accurate information to improve their work” (National Center for Cultural Competence, 2000).

The Benefits and Challenges of Community-Based Research

3.1 Benefits

In *Forging Collaborative Partnerships to Enhance Family Health: an Assessment of Strengths and Challenges in Conducting Community Based Research*, Caldwell et al. (2001) describe the process of community collaboration as experience in the development and conduct of a demonstration project. In this section of the report we present both the benefits and challenges to this approach of research.

3.1.1 Benefits for Researchers

- With the cooperation of the community, attrition in longitudinal studies may decrease. In a collaborative study between a university and a community-based health agency surveying for breast and cervical cancer screening behavior among Korean women, community participation along with cultural sensitivity and competence contributed to a 79% response rate (Chen et al., 1997).
- The primary benefit of engaging in collaborative research partnerships with communities, especially communities of color, is that the needs of the residents will be addressed more adequately in their terms rather than defined solely by researchers' interests (Caldwell et al., 2001).
- Having community-based organizations as participating partners allows for assessments based on more locally accurate information, a broader knowledge of the community, and an empathetic understanding of community residents' concerns (Caldwell et al., 2001).
- With its attention to action as an integral part of the research process, CBPR further encourages epidemiology to expand beyond a science that measures associations of exposure and disease, to become a data-driven approach to improve community health and well-being (Leung et al., 2004).
- By adopting a participatory population perspective (to research) that emphasizes the social influences on health and disease, epidemiology is in a position to reassert its public health roots by (1) extending the search for causes from the individual to the community and to sociopolitical systems, (2) broadening the methodologies to include qualitative and participatory research methods, and (3) integrating lay knowledge into scientific knowledge (Nuffield Institute for Health, 1993).
- Community representatives can assist in making the project more culturally relevant and more widely accepted by their neighbors (Caldwell et al., 2001).
- Including the health department helps to ensure that a community's health concerns will be identified more accurately using local and current epidemiological data and that community resources and service needs will be considered (Caldwell et al., 2001).
- Increased participation (as the result of community involvement) means more data and greater statistical power for epidemiologists. The importance of such increased statistical power is particularly underscored in epidemiological studies looking at racial/ethnic differences in health outcomes and in which low response rates from already numerically

smaller groups often lead to the dropping of these groups and/or aggregating of participants into an "other" category (Newacheck and Halfon, 1998).

- Researchers can provide theoretical guidance for data collection and situate the data collection within the context of current research in the field (Caldwell et al., 2001).
- Community acceptance of the researchers is enhanced (Caldwell et al., 2001).
- The research skills of the lay community partners and their understanding of the research process are enhanced (Caldwell et al., 2001).
- Researchers have increased opportunities to benefit from community expertise (Caldwell et al., 2001).
- Findings from epidemiological studies can be made locally relevant and context specific, which is particularly important in the development of meaningful policy and practice. For example, as gun violence was becoming a major public health issue in the United States, participation and collaborative research and action on the part of community-based organizations, grassroots advocates, health professionals, and law enforcement resulted in a policy decision to better protect the public from guns (Wallack, 1999).
- Connecting and communicating with community members creates a truly community-driven process (Caldwell et al., 2001).
- Community ownership in projects helps validate epidemiological findings and the acceptance of epidemiological instruments in the community (Thompson et al., 2000).
- Community-driven processes lead to collective thinking and ultimately may produce more innovative, effective, and sustainable solutions to complex problems (Caldwell et al., 2001).
- Equal partnership between researchers and communities will increase the likelihood for a successful project with mutual benefits (Israel et al., 1998).
- Partners with diverse skills, knowledge, expertise, and sensitivities are brought together to address complex problems (Butterfoss et al., 1993; Hall, 1992; Himmelman, 1992; Israel et al., 1989; Schensul et al., 1987).
- The limitations of the concept of "value-free" science (Denzin 1994) are recognized, and self-reflexive, engaged, and self-critical role of researchers are encouraged (Denzin 1994; Reason 1994; Zich et al. 1986).
- The possibility of overcoming understandable distrust of research on the part of communities that have historically been subjects of such research is increased (Hatch et al., 1993; Schulz et al., 1998).

3.1.2 Benefits to the Community

Benefits to the community include the following:

- Ongoing community resident commitment and participation builds ownership in the process and its outcomes (Thompson et al., 2000).
- Community-driven processes lead to collective thinking and ultimately may produce more innovative, effective, and sustainable solutions to complex problems (Caldwell et al., 2001).
- Community engagement and empowerment through the MAPP (asset identification) process may benefit community involvement in other community initiatives.

- Community residents and subpopulations may gain a better awareness of themselves, the area in which they live, and their own potential for improving their quality of life (Caldwell et al., 2001).
- Additional funds and possible employment opportunities are provided for community partners (Altman 1995; Nyden et al., 1992; Schulz, 1998).
- Communities that have been marginalized on basis of race, ethnicity, class, gender, and sexual orientation are involved (deKoning et al., 1996; Gaventa, 1993; Hatch et al., 1993; Krieger, 1994; Marguire, 1987; Vega, 1992; Williams et al., 1995).

3.2 Challenges

A more effective and efficient use of time is gained when basic issues are clarified and a group has developed a shared understanding. Dialogue can be used strategically to help a group make the best use of its time. In our increasingly fast-paced lives, it is often difficult to take the time to hold a dialogue and truly listen to each other. It is necessary, therefore, to keep in mind the benefits that ultimately will be gained from taking the time to establish community connections and build a community-driven process.

3.2.1 Communication

Participants may have negative feelings and disbelief regarding a community-driven process, particularly if the community has had negative experiences at such attempts previously. Because these feelings are often the result of apprehension and uncertainty, it is important to allow time to address such issues.

Engage a facilitator—someone who has experience with group dynamics and or organizational skills. The facilitator will be viewed as neutral and able to move the group forward without bias. A skilled facilitator will put everyone at ease by stating what the session will entail, rules for sharing, the length of the meeting, and how to proceed after the meeting.

Some other challenges that partners face when applying the concepts and principles that frame community-based research include the following:

- **Building trust and respect among the collaborators.** This requires a commitment of resources on the part of the researchers. A thoughtful and respectful entry into the community must be made; for example, a series of meetings to explain the study design and future plans should be scheduled as soon as possible. During the community meetings, expectations for the collaboration around the study should be discussed with time allowed for questions and answers. Options for partners' involvement should be presented (e.g., advisory board positions, opportunity to host the study). Researchers should solicit input from the community and listen and address the community's concerns and expectations for the study.
- **Negotiating the distribution of control and power.** This level of negotiating requires a complete paradigm shift for most researchers and lay persons. By definition, a CBR project requires an equitable arrangement for the decision process of the study. Further, it assumes that the researchers acknowledge, support, and encourage the exchange of ideas from the lay collaborators or partners throughout the study.
- **Resolving conflicts associated with the differences in perspective, priorities, assumptions, values, beliefs, and language.** "Creative conflict" is a part of any group dynamic. However, the partners can plan for this occurrence and lessen its negative

impact by using organizational developmental tools and communication strategies throughout the life of the study.

- **Resolving conflicts associated with different emphases on task and process.** Holding regular collaborator meetings with a trained facilitator will keep people on task and help identify conflicting issues.
- **Managing time and human resources.** Community partners run the risk of being overburdened with project-related responsibilities that could interfere with their daily responsibilities. Study protocol design must address the roles of partners and the environment in which they will work and live during the study. Soliciting feedback on the study design from the partners provides a reality check of sorts. Once this is done assignments can be made more practical, and the opportunity to stay on schedule and/or to succeed at the assignment is greater.

Community organizations may not have an infrastructure capable of handling the additional tasks and fiduciary responsibilities associated with the project. This is a perfect opportunity to demonstrate the exchange of resources between collaborators. Additionally, this should not come as a surprise to the study team because this need would have been identified during the inventory of partner assets. As a part of the supportive and/or capacity-building goals, another partner can provide guidance in developing this capability.

- **Deciding how to define the community.** This critical definition, which must be agreed upon by the collaborators, will drive many of the strategies (e.g., recruitment, data collection methodology, and methods of communication).
- **Deciding who represents the community.** Once the community has been defined, it will be easier to understand who its representatives are. Most likely, a number of different people will be required to represent different factions of the community. It is important to understand not only who they are, but also how they represent the community and under what circumstances.
- **Finding the time to meet.** Finding convenient meeting times for all partners is difficult, but not impossible. It may require that the meeting piggyback on another community function that is expected to have a good turnout such as back to school, civic association, or 4H Club meetings. It may also require the researchers to attend meetings outside of their normal work days and/or hours in order to accommodate the other partners. Such unconventional accommodations for the community partners go a long way in terms of “good will.”

3.2.2 Study Design

One of the greatest challenges facing CBR collaborations today is how to translate the definitions and guiding principles of CBR into scientific application. The literature shows that there is concern on the part of researchers and funding agencies that CBR studies are less rigorous research endeavors and, in the worst case scenario, cannot be evaluated. Viswanathan and colleagues (2004), while measuring improved research quality outcomes of CBR, were able to document evidence of either enhanced or diminished research quality attributable to the CBR method. They found that there is reason for researchers to continue “...to seek the best possible balance between research methodology and community collaboration.” They note the number of recent CBPR projects funded by the federal government and the associated publishing demand for the findings. They recommend that the reporting system for CBPR studies be more structured to improve the quality of the reports. They believe that CBR studies can and should be grounded in the same sound scientific

requirements that one would hold for any other investigation. That is, the development and testing of hypotheses and consideration of study design remain as critical and essential to this model of research as to any other.

Conclusion

We found a great deal of information and resources on community-based research. In fact, there was far more information than time allowed to complete this assignment. As RTI became immersed in this plethora of material and resources, we remained focused on the four questions raised by the NCS planners:

- What are the strengths and weaknesses that may exist in a study design that depends on community involvement to conduct various aspects of the NCS?
- What steps might the planners take to build or strengthen the capacity at local CBR sites that would allow them to work with communities on the NCS?
- What recommendations can be made to the planners that will further address the concept of partnering with the community as part of the NCS?
- What are the most advantageous vehicles for involving the community?

Overall, we find that communities have demonstrated, through the numerous CBR projects throughout the United States, their desire to become more involved with research studies that impact their lives. They want to take greater ownership and control over decisions affecting their health, and they realize that can only happen if they are involved in the planning and implementation stages of a study. Researchers have also demonstrated their desire to involve the community in the full life cycle of a study. However, it would be naïve to think that this type of collaboration would be a seamless union. The following discussion identifies the inherent strengths and weaknesses of a community-based research approach and ways that the NCS planners can offset the weaknesses.

4.1 Strengths and Weaknesses

Strengths and benefits to employing a study design that involves the community throughout the study include the following:

- Collaboration between the research team and the community will help to better identify problems and issues, which will ultimately produce better data.
- Community participation provides an opportunity for reciprocal education between the community and researchers.
- Community input ensures community buy-in, which ensures better participation and retention.

Weaknesses or challenges in using a study design that depends on community involvement include the following:

- Working with the community requires more time and resources. That is, tasks take longer to complete because there is an additional level of communication that must occur when another collaborator (the community) is included in the loop.
- Community partners do not always follow the “plan.” There must be some flexibility in the protocol to allow for instances when the partners do not follow the plan as outlined before launching the study.

4.2 Steps That NCS Planners Might Take To Build and/or Strengthen Capacity

The various sites around the United States have different capabilities for CBR. That is, sites that have been participating in community-based research for years appear to have developed an infrastructure to support the concept. Their community partners are fairly sophisticated, staffing and funding is blended in order to stretch resources, the community participates, and the initiatives report progress. On the other hand, at sites new to CBR, the resources for technical expertise are limited or not present, staffing and funding are problematic, and the community feels dismayed and does not participate at the expected levels of their study's planners.

Once the NCS planners know which sites have been chosen for the study, we suggest the following steps to build or strengthen the capacity of the site:

- Conduct a needs assessment or community asset inventory to discern the resources and deficiencies.
- Develop and/or enhance community advisory boards at the sites.
- Provide technical assistance to the sites for the required areas identified as deficient or absent (e.g., community advisory board training).
- Develop an interactive website for the NCS where the community can find answers to their questions about the study, access information that will provide resources to the community, and provide them with the opportunity to be heard by the research team.
- Assist the sites in producing a newsletter specific to the local study site for the purpose of providing study updates and maintaining community interest in the study once it is implemented.
- Host a series of NCS briefings in the community to bring them up to date with the progress and future plans.
- Provide a facilitator to assist in the event of communication bottlenecks at the sites.

4.3 Options for NCS Planners to Consider for Partnering with the Community on NCS

The following are approaches for building this partnership:

- Recruit community representatives to serve on a community advisory board that will provide feedback to the researchers on instrument development, recruiting strategies, and data collection methodology.
- Recruit community representatives at each site to serve on a study implementation council that will help identify community resources (including people) to be used in the implementation of the NCS. This is clearly a capacity-building function—because the council will receive training to perform their charge to identify existing community resources and integrate those resources into the conduct of the study, they will learn how to connect and employ resources.
- Consider using some of the existing community agencies, institutions, and organizations to serve as a host study site.

- Hire members of the community for study positions. These positions should be reflective of the myriad roles needed to operate a study of this magnitude and not limit the community to “data collector slots.” This is another way to leave the community in a better position than before the study entered the community.

4.4 Most Advantageous Methods to Involve the Community in NCS at this Point

RTI believes that the following methods would be most advantageous to study planners in soliciting the assistance of communities at each study site:

- Invite the community to a debriefing session on the NCS.
- Assist the local site in establishing an advisory board for the NCS.
- Invite key community representatives to serve on the local community advisory board to review and comment on the implementation strategies for the study. NCS planners will need specific intelligence about each community in order to guarantee the highest level of participation and retention. The greater the level of initial input from the community to the NCS planners, the greater the success of the study.
- Provide technical assistance to the local site to help them inform the community about the NCS (e.g. public information campaign).
- Provide funding for local sites to hire community people to maintain the skill sets that the technical assistance has established and a method of mentoring those skill sets beyond the site visit.

4.5 Issues for Further Exploration

For the NCS planners to completely understand the ramifications of involving the community at different levels in the NCS, they will need to explore the following areas:

- A standard method for monitoring and reporting CBR progress and study outcomes needs to be developed to ensure the integrity of the research methodology.
- The researchers need to develop CBR competency. It is not likely that all of the researchers involved in the NCS have experience in CBR and most likely have some concerns that should be addressed by the NCS study planners before the researchers develop their protocols.
- More specific information on how to obtain and maximize the participation of Native Americans in the NCS, in terms of community partnerships, should be gathered. The Internet is a good source of information; another means of obtaining this information is to conduct focus groups with both the potential participants and key representatives from the various tribes and nations.

Recommendations

We understand that the NCS planners need to assess the existing capabilities of potential local community-based research sites to engage the community and integrate community interests into the research agenda. More specifically, the planners need to know the optimal entry points for community involvement the NCS and the ramifications of that involvement. We have reviewed the literature and performed an Internet search to identify and gather information on existing CBR programs throughout the United States. Once the sites are selected for the NCS, we recommend that the the planners engage the community through the following actions before the study is launched:

- Identify community resources and recruit partners
- Engage/involve the partners
- Build trust.

5.1 Identify Community Resources and Recruit Partners

The following approaches are ways we recommend for identifying community resources and recruiting partners:

- With time being of the essence, we recommend the planners consider sending an advance survey team to each site to gather pertinent information about the community. The team needs to inventory the community's resources and determine the key representatives. This will provide the planners with the information they need to recruit the appropriate partners.
- We recommend using listening sessions as a method of collecting data about the community and identifying potential partners.
- We suggest publicizing the study at a town meeting. Town meetings give people of diverse backgrounds a chance to express their views and are also a first step toward understanding the community's needs and resources. A good public forum informs the group of where the community is and where the members would like to go.

5.1.1 Engage/Involve the Community Partners

There are several ways to ensure community involvement:

- Recruiting influential people is another approach to consider to become supportive and involved in the NCS. This may actually be less of a challenge than might be expected because of the nature of the study and the level of interest already surrounding the study. The important issue here is to be clear about the role these key partners will have in the study.
- We suggest the planners offer more than one way for a person to be involved. On the NCS, key partners can provide support in any of the following ways:
 - They can become members of an advisory board.
 - They can act as spokespersons for the organization in particular situations.
 - They can host a study site.

- They can perform specific tasks pro bono—legal work, accounting, etc.
- They can act as liaisons to particular sectors of the community where they have influence—special populations, the business community, people in public housing, etc.
- They can advocate with local and state government for funding or support.
- They can lend their names to and help organize events around the NCS.

5.2 Building Trust

The following are recommendations of ways the study team might earn the trust of the community:

- We recommend that the planners assist the study team in developing a presence in each of the selected communities.
- We recommend that the study team receive and inform the community of endorsement from key community representatives.
- We also suggest that the study publicize the endorsement of the study by persons of national prominence.

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Appendix A: Glossary of Terms

APEXPH: Assessment Protocol for Excellence in Public Health. A community assessment and planning tool developed by the National Association of County and City Health Officials (NACCHO) for use by local health departments and other organizations.

Asset Mapping: A tool for mobilizing community resources. It is the process by which the capacities of individuals, civic associations, and local institutions are inventoried.

BRFSS: Behavioral Risk Factor Surveillance Survey. A national survey of behavioral risk factors conducted by states with CDC support.

Community: The aggregate of persons with common characteristics such as geographic, professional, cultural, racial, religious, or socio-economic similarities; communities can be defined by location, race, ethnicity, age, occupation, interest in particular problems or outcomes, or other common bonds. (Adapted from Turnock's *Public Health: What It Is and How It Works*.)

Community Assets: Contributions made by individuals, citizen associations, and local institutions that individually and/or collectively build the community's capacity to assure the health, well-being, and quality of life for the community and all its members.

Community Based Participatory Research (CBPR): 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 by taking action, including social change. (Viswanathan et al., 2004).

Community Based Research: In public health is a partnership approach to research, which equitably involves community members, community organization representatives, and researchers in all aspects of the research process to enhance understanding of a given phenomenon and to integrate the knowledge gained with action to improve the health and well being of community members (Israel et al., 1998).

Community Collaboration: A relationship of working together cooperatively toward a common goal. Such relationships may include a range of levels of participation by organizations and members of the community. These levels are determined by: the degree of partnership between community residents and organizations, the frequency of regular communication, the equity of decision making, access to information, and the skills and resources of residents. Community collaboration is a dynamic, ongoing process of working together, whereby the community is engaged as a partner in public health action.

Community Engagement: The process of working collaboratively with groups of people who are affiliated by geographic proximity, special interests, or similar situations with respect to issues affecting their well-being (CDC/ATSDR Committee on Community Engagement, 1997).

Community Health: A perspective on public health that assumes community to be an essential determinant of health and the indispensable ingredient for effective public health practice. It takes into account the tangible and intangible characteristics of the community – its formal

and informal networks and support systems, its norms and cultural nuances, and its institutions, politics, and belief systems.

Community Health Improvement Process: Community health improvement is not limited to issues classified within traditional public or health services categories, but may include environmental, business, economic, housing, land use, and other community issues indirectly affective the public's health. The community health improvement process involves an ongoing collaborative, community-wide effort to identify, analyze, and address health problems; assess applicable data; develop measurable health objectives and indicators; inventory community health assets and resources; identify community perceptions; develop and implement coordinated strategies; identify accountable entities; and cultivate community "ownership" of the entire process.

Community Health Profile: A comprehensive compilation of measures representing multiple categories that contribute to a description of health status at a community level and the resources available to address health needs. Measures within each category may be tracked over time to determine trends, evaluate health interventions or policy decisions, compare community data with peer, state, nation, or benchmark measures, and establish priorities through an informed community process.

Community Partnerships: A continuum of relationships that foster the sharing of resources, responsibility, and accountability in undertaking activities within a community.

Community Support: Actions undertaken by those who live in the community that demonstrate the need for and value of a healthy community and an effective local public health system. Community support often consists of, but is not limited to, participation in the design and provision of services, active advocacy for expanded services, participation at board meetings, support for services that are threatened to be curtailed or eliminated, and other activities that demonstrate that the community values a healthy community and an effective local public health system.

Core Indicators: Data elements that MAPP recommends all communities collect and track. The core indicators have a higher priority based on the critical nature of the data, potential for comparative value, and relevance to most communities.

Determinants (or Risk Factors): Direct causes and risk factors which, based on scientific evidence or theory, are thought to influence directly the level of a specific health problem.

Dialogue: The skillful exchange or interaction between people that develops shared understanding as the basis for building trust, fostering a sense of ownership, facilitating genuine agreement, and enabling creative problem solving.

Environmental Equity: The distribution and effects of environmental problems and the policies and processes to reduce differences in those who bear environmental risks. In contrast to environmental racism, equity includes consideration of the disproportionate risk burden placed on any population group, as defined by gender, age, income, and race.

Environmental Health Indicators: The physical environment directly impacts health and quality of life. Clean air and water, as well as safely prepared food, are essential to physical health. Exposure to environmental substances, such as lead or hazardous waste, increases risk for preventable disease. Unintentional home, workplace, or recreational injuries affect all age groups and may result in premature disability or mortality. This is a category of data recommended for collection within the Community Health Status Assessment.

Environmental Justice: The fair treatment and meaningful involvement of all people, regardless of race, ethnicity, culture, income or education level with respect to the

development, implementation, and enforcement of environmental laws, regulations, and policies. Environmental justice seeks to ensure that no population is forced to shoulder a disproportionate burden of the negative human health and environmental impacts of pollution or other environmental hazards.

Epidemiology: “The study of the distribution and determinants of health-related states or events in specified populations, and the application of this study to control of health problems.” (Last 1988).¹

Ethnicity: The classification of a population that shares common characteristics, such as religion, traditions, culture, language, and tribal or national origin.

Health Promotion Activities: Any combination of education and organizational, economic, and environmental supports aimed at the stimulation of healthy behavior in individuals, groups, or communities.

Health Resource Availability: Factors associated with health system capacity, which may include both the number of licensed and credentialed health personnel and the physical capacity of health facilities. In addition, the health resources category includes measures of access, utilization, and cost and quality of health care and prevention services. Service delivery patterns and roles of public and private sectors as payers and/or providers may also be relevant. This is a category of data recommended for collection within the Community Health Status Assessment.

Health Status Indicator: A single measure that purports to reflect the health status of an individual or defined group.

MAPP: Mobilizing for Action through Planning and Partnerships. A community-wide strategic planning tool developed by NACCHO and CDC.

NACCHO: National Association of County and City Health Officials. www.naccho.org

NIOSH: The National Institute for Occupational Safety and Health is an agency within CDC. www.cdc.gov/niosh

PACE-EH: Protocol for Assessing Community Excellence in Environmental Health. A community environmental assessment and planning tool developed by NACCHO to assist local health departments and their communities in prioritizing environmental health risks.

Participatory Action Research (PAR): “...a systematic investigation, with the collaboration of those affected by the issue being studied, for the purposes of education and taking action or effecting social change.”²

Public Health: “...the science and the art of preventing disease, prolonging life, and promoting physical health and mental health and efficiency through organized community efforts toward a sanitary environment; the control of community infections; the education of the individual in principles of personal hygiene; the organization of medical and nursing service for the early diagnosis and treatment of disease; and the development of the social machinery to ensure to every individual in the community a standard of living adequate for the maintenance of health.” (C.E.A. Winslow).³

¹Last, John M., A Dictionary of Epidemiology, edited for the International Epidemiological Association, 2nd ed. New York: Oxford University Press, 1988.

²Green LW, George MA, Frankish CJ, Herbert CJ, Bowie WR, O’Neil M. Study of participatory research in health promotion: review and recommendations for the development of participatory research in health promotion in Canada. Ottawa: Royal Society of Canada; 1995.

³Winslow, Charles-Edward Amory, Man and Epidemics. Princeton, N.J.: Princeton University Press, 1952.

Public Participation: The involvement of citizens in governmental decision-making processes. Participation ranges from being given notice of public hearings to being actively included in decisions that affect communities. See community collaboration.

Risk Communication: An interactive process of sharing knowledge and understanding so as to arrive at well-informed risk management decisions. The goal is a better understanding by experts and non-experts alike of the actual and perceived risks, the possible solutions, and the related issues and concerns.

Sentinel Health Event: Sentinel events are those cases of unnecessary disease, disability, or untimely death that could be avoided if appropriate and timely medical care or preventive services were provided. These include vaccine-preventable illness, late stage cancer diagnosis, and unexpected syndromes or infections. Sentinel events may alert the community to health system problems such as inadequate vaccine coverage, lack of primary care and/or screening, a bio-terrorist event, or the introduction of globally transmitted infections. This is a category of data recommended for collection within the Community Health Status Assessment.

Social Capital: A “composite measure” which reflects both the breadth and depth of civic community (staying informed about community life and participating in its associations) as well as the public’s participation in political life. It is characterized by a sense of social trust and mutual interconnectedness, which is enhanced over time through positive interaction and collaboration in shared interests.

Socioeconomic Characteristics: Socioeconomic characteristics include measures that have been shown to affect health status, such as income, education, and employment, and the proportion of the population represented by various levels of these variables. This is a category of data recommended for collection within the Community Health Status Assessment.

Social and Mental Health: This category represents social and mental factors and conditions which directly or indirectly influence overall health status and individual and community quality of life. This is a category of data recommended for collection within the Community Health Status Assessment.

Sponsors: Key organizations and individuals that offer strong initial support to an initiative.

Stakeholders: All persons, agencies and organizations with an investment or ‘stake’ in the health of the community and the local public health system. This broad definition includes persons and organizations that benefit from and/or participate in the delivery of services that promote the public’s health and overall well-being.

Surveillance: The systematic collection, analysis, interpretation, and dissemination of health data to assist in the planning, implementation, and evaluation of public health interventions and programs.

Sustainability: The long-term health and vitality — cultural, economic, environmental, and social — of a community. Sustainable thinking considers the connections between various elements of a healthy society, and implies a longer time span (i.e., in decades, instead of years).

Appendix B: Resources and References for CBR

Through the Internet search and literature review on this work assignment to identify and assess existing linkages with local communities among potential research sites for the NCS, we identified the following programs and/or sources for supporting community based research . The list is grouped topically.

Healthy Communities Initiatives

- **National Association of County Health Officials. Assessment Protocol for Excellence in Public Health. Washington, DC: NACCHO, 1991.**

The *APEXPH* tool guides local health departments through three activities: 1) an internal organizational capacity assessment of the local health department; 2) a collaborative community health assessment process that incorporates the use of quantitative and qualitative data; and 3) a process for monitoring and evaluating the first two processes, as well as ensuring that the resultant activities are kept alive. Several other resources from NACCHO also provide useful information for “Healthy Communities” efforts.

- **National Association of County and City Health Officials. Assessment to Action: A Tool for Improving the Health of Communities Affected by Hazardous Waste. Washington, DC: NACCHO, 2002.**

Assessment to Action facilitates collaboration between local public health agencies and communities in decision making throughout an assessment process. It provides steps and methods to assess community needs and concerns related to hazardous waste sites, and formulate action steps for addressing environmental health concerns.

For more information contact:

The National Association of County and City Health Officials Publications Department
1100 17th Street, 2nd Floor
Washington, DC 20036
Tel: 202-783-5550, ext. 237 (publications department)
Fax: 202-783-1583
Email: info@naccho.org
<http://www.naccho.org>

- **The Coalition for Healthier Cities and Communities**

This coalition is a network of partnerships and organizations working to build healthier communities by developing and distributing resources that support healthy communities initiatives. A recent resource, A Call to Action, encourages communities to undertake healthy communities’ initiatives.

For more information contact:

The Coalition for Healthier Cities and Communities
One North Franklin
Chicago, IL 60606
Tel: 312-422-2618 Fax: 312-422-4568

Email: info@healthycommunities.org <http://www.healthycommunities.org>

Identifying Community Assets

- **Asset-Based Community Development (ABCD) Institute: Northwestern University**

The ABCD Institute focuses on the production of resources and tools for community builders involved in the process of capacity-based initiatives, helping them identify, nurture, and mobilize neighborhood assets. It believes community assets are key building blocks in sustainable urban and rural community revitalization efforts. These community assets include the skills of local residents, the power of local associations, the resources of public, private, and non-profit organizations, and the physical and economic resources of local places.

For more information contact:

Asset-Based Community Development Institute
Northwestern University
2040 Sheridan Rd
Evanston, IL 60208
Tel: 847-491-8711
Fax: 847-467-4140
<http://www.nwu.edu/IPR/abcd.html>

- **The Health Forum**

The Health Forum is a new enterprise created through the union of The Healthcare Forum and the American Hospital Association's publishing and data and information subsidiaries. The organization provides information on building healthy communities. One of its products is the Outcomes Toolkit, an interactive software program designed to facilitate a healthy community effort by providing tools and information, as well as worksheets for inputting information.

For more information contact:

The Health Forum
425 Market Street, 34th Floor
San Francisco, CA 94105
Tel: 800-821-2039
Email: hfcustsvc@healthforum.com
<http://www.healthforum.com/>

- **Public Participation and Accountability Subcommittee, National Environmental Justice Advisory Council. *The Model Plan for Public Participation*. Washington, DC: Environmental Protection Agency, 1996.**

This small booklet outlines the importance of public participation in decisions that affect human health and the environment. The Model Plan provides recommendations for methods for institutionalizing public participation in community and environmental activities. Sections include: guiding principles, critical elements, core values, and a checklist for public participation.

For more information contact:

Office of Environmental Justice
401 M Street, SW
Washington, DC 20460
Tel: 202-564-6982 Fax: 202-501-1480 <http://www.epa.gov/compliance>

- **Kretzmann, John P, and McKnight, John L. Building Communities from the Inside Out: A Path Toward Finding and Mobilizing A Community's Assets. Chicago, IL: ACTA Publications, 1993.**

This resource focuses on asset building as part of broad-based community development initiatives. It provides information and tools for identifying and releasing individual and organizational capacities and assets. Other resources available through ACTA publications include:

- A. "Mobilizing Community Assets" (set of video training tapes)
- B. "A Guide to Mapping Local Business Assets and Mobilizing Local Business Capacities"
- C. "A Guide to Mapping Consumer Expenditures and Mobilizing Consumer Expenditure Capacities"
- D. "A Guide to Evaluating Asset-Based Community Development: Lessons, Challenges, and Opportunities"
- E. "A Guide to Capacity Inventories: Mobilizing the Community Skills of Local Residents"

For more information contact:

ACTA Publications
4848 North Clark Street
Chicago, IL 60640
Tel: 800-397-2282
Fax: 800-397-0079
<http://www.nwu.edu/IPR/abcd.html>

- **Centre for Research and Education in Human Services**

Has produced a handbook on things non-profit organizations can do to improve their sustainability. The manual covers partnership building, leadership and governance, relevance/research, and organizational culture, but applies a CBPR approach or philosophy to all four. It can be downloaded for free from:

<http://www.crehs.on.ca/downloads/sustainability%20manual.pdf>

For more information contact:

Andrew Taylor
Centre for Research and Education in Human Services
73 King St. W., Kitchener, ON, N2G 1A7
p 519 741 1318 f 519 741 8262
andrew@crehs.on.ca www.crehs.on.ca

Evaluation/Assessment Tools

- **National Association of County and City Health Officials. *Protocol for Assessing Excellence in Environmental Health (PACE-EH)*. Washington, DC: NACCHO, 1999.**

The PACE-EH document outlines a methodology for conducting community environmental health assessments. A crucial component of the PACE-EH methodology is gathering input and feedback from the community regarding perceived environmental

health issues; it is this input that drives the development of environmental health indicators and gathering of data.

For more information contact:

The National Association of County and City Health Officials, Publications Department
1100 17th Street, 2nd Floor
Washington, DC 20036
Tel: 202-783-5550, ext. 237
Fax: 202-783-1583
Email: info@naccho.org
<http://www.naccho.org>

- **Institute of Medicine. *Improving Health in the Community: A Role for Performance Monitoring*. Washington, DC: National Academy Press, 1997.**

Provides an overview of the importance of performance measurement for public health systems within a community health improvement process. Discusses measurement tools, and provides potential measures for various public health issue areas.

To order this reference contact:

The National Academy Press
2101 Constitution Ave., NW
Washington, DC 20055
Tel: 202-334-3313
Fax: 202-334-1891
Email: zjones@nas.edu
<http://www.nap.edu>

- **National Association of County Health Officials. *Assessment Protocol for Excellence in Public Health*. Washington, DC: NACCHO, 1991.**

The APEXPH tool presents a basic community health assessment approach that incorporates the use of quantitative and qualitative data. A broad-based, community health committee should lead the process.

- **For more information contact:**

National Association of County and City Health Officials Publications Department
1100 17th Street, 2nd Floor
Washington, DC 20036
Tel: 202-783-5550, ext. 237 (publications department)
Fax: 202-783-1583
Email: info@naccho.org
<http://www.naccho.org>

- **National Association of County and City Health Officials. *Protocol for Assessing Community Excellence in Environmental Health*. Washington, DC: NACCHO, 2000.**

The PACE EH tool provides guidance and tools for conducting a community planning process focusing on environmental health. The tool provides decision-makers with a community-based methodology for evaluating and characterizing local environmental health conditions, identifying populations at risk of environmental exposure, and prioritizing local programs and policies.

For more information contact:

National Association of County and City Health Officials Publications Department
1100 17th Street, 2nd Floor
Washington, DC 20036
Tel: 202-783-5550, ext. 237 (publications department)
Fax: 202-783-1583
Email: info@naccho.org
<http://www.naccho.org>

- **Community Health Status Indicators Project**

The Community Health Status Indicators (CHSI) Project offers county-specific reports on community health status for every county in the United States. The goal of the CHSI Project is to provide important health and health-related data in a way that makes them useful to communities. The data in the CHSI report have been cross-walked with the core indicators in MAPP. A collaborative activity of ASTHO, NACCHO, and PHF with funding from the Health Resources and Services Administration (HRSA), the CHSI reports are an excellent source of data for many core indicators.

For more information about the CHSI project visit the website –
<http://www.communityhealth.hrsa.gov>

- **The Studies Circles Resource Guide- for in-depth conversations on important community issues at**

<http://www.hospitalconnect.com/healthycommunities/usa/index.html>

For additional resources and information on hosting a dialogue and community -building in general: <http://www.hospitalconnect.com/healthycommunities/usa/index.html>

Multi-Cultural Information

- **Fiscella, Kevin, Franks, Peter, Gold, Marthe R, and Clancy, Carolyn M. “Inequality in Quality: Five Principles for Addressing Disparities through Performance Measures.” JAMA 283:2579-2584, 2000.**

While socioeconomic and racial/ethnic disparities in health care quality have been extensively documented, there is little current effort to monitor and address disparities through organizational quality improvement initiatives, according to the authors of a recent article in the Journal of the American Medical Association (JAMA). In response, they have proposed five principles for addressing disparities through quality performance measures: 1) Disparities must be recognized as a significant quality problem. 2) The collection of relevant and reliable data are needed to address disparities. 3) Beginning with existing quality measures such as HEDIS, performance measures should be stratified by socioeconomic position and race/ethnicity for public reporting. 4) Population-wide performance measures should be adjusted for socioeconomic position and race/ethnicity. 5) An approach to disparities should account for the relationships between morbidity and both socioeconomic position and race/ethnicity.

- **REACH 2010**

REACH, which stands for “Racial and Ethnic Approaches to Community Health (REACH 2010), is a CDC demonstration project that targets six health priority areas: infant mortality, breast and cervical cancer, cardiovascular disease, diabetes, immunization, and HIV/STD. The purpose of the project is for communities to mobilize and organize

their resources in support of effective and sustainable programs that will eliminate the health disparities of racial and ethnic minorities. Some REACH grantees are addressing the burden of diabetes in American Indian communities including the Eastern Band of the Cherokee Nation and the Oklahoma State Health Department.

For more information about this topic contact:

Randy Katsoyannis
202.690.8598

Recruiting Information

- Brown, M. (1994). How to Recruit People to Your Organization. Cambridge, MA: Michael J. Brown.
- Homan, M. (1994). Promoting Community Change: Making it happen in the real world. Pacific Grove, CA. Brooks/Cole.
- Rutgers University Center for Social and Community Development.(1993). Urban Community Development Projects: Instruments and tools

Additional CBR Resources

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Appendix B.1: Example of a Memorandum of Understanding

Memorandum of Understanding between the [*university/research organization*] and the [*community based organization*] concerning Program Collaboration for [*identify research interest*].

The [*university/research organization*] has an on-going commitment to address the concern of [*interest*] in the state. Such [*interest*] related problems threaten the health of our community. The purpose of [*university/research organization*] is to develop a [*fill in*] program that would provide [*Identify target population*] with [*fill in what you intend to do for the study population and how*]. Through [*community based organization*], the [*university/research organization*] will provide leadership and coordination, and can provide communities with the tools and technical

assistance they need to develop practical solutions to their unique [interest] problem. The mission of [name of research program]:

- As a result, this Memorandum of Understanding was created to delineate the cooperative agreement between [university/research organization] and [community-based organization].

On an as-authorized, as-funded, as-available, best-effort basis and at no charge to [university or name of research program], the [community-based organization] agrees to:

1. Work cooperatively to address the issue of community [interest]-related problems and to share resources, as appropriate.
2. Jointly collect data that will help identify the scope and nature of the problems in the county, focus strategies, and address the issue of community [interest]-related problems through community participatory research.
3. Share information on grant funding opportunities and submit joint grant proposals, as appropriate.
4. Develop joint [interest] education, training, and prevention programs for community members, working with the regional and statewide programs.
5. Meet at least once each calendar year, to review the status, accomplishments and future goals of the cooperative agreement.
6. Each party shall acknowledge the participation of the other party in its public information releases arising from or concerning this MOU. Each party shall provide prior written notice to the other party, and the text when reasonable, of public information releases which arise from this MOU and which refer to the other party or any employees thereof by name or title.
7. Increase the capacity of communities to enhance their own well-being
8. Create, manage, and evaluate the effectiveness of a program designed to solicit interested citizens throughout the county to participate in an annual program that helps the citizens of the community understand the concept of, appreciate the need for, and support the implementation of the approach to sustainable cancer awareness

RESPONSIBILITIES of [*university/research organization*]:

- Help identify [*interest*]-related problems in your community
- Collaboratively establish [*interest*] control priorities
- Identify and fill gaps in service
- Collaboratively develop improved communication with local health care providers
- Collaboratively develop intervention strategies that fit your community's unique needs
- Build capacity
- Help identify resources within the state and nationally to provide technical assistance for development of sustainability
- Provide the tools, technology, protocols and assistance needed to equip and prepare [*interest*] Councils to collect, analyze, and archive selected qualitative and quantitative data
- Assist in the over-all improvement of the health status of individuals, communities, and the region.

RESPONSIBILITIES of [*community-based organization*]:

- Identify key community leaders with in the community to help change [*interest*] health disparities
- Establish common goals, mission, and vision
- Establish specific calendar and time schedules prior to program development and implementation in order to carry out the objectives of this MOU.
- Provide a location where resource materials and demonstrations can be made available to anyone who is interested in the promotion of a sustainable approach to cancer awareness
- Meet monthly
- Attend steering committee meetings

For [<i>community-based organization</i>]:	For [<i>university/research organization</i>]
Name:	Name:
Signature:	Signature:
Date:	Date:

Source: CCPH, 2004.

Appendix B.2: SAMPLE Partnership Agreement

Research Partnership Agreement *[Name of Research Project]*

Background

This agreement outlines the rights and obligations of the *[community organization]* and the researcher for the project: *["Name of Research Project"]* with respect to the process for this research project. This research partnership agreement is effective from *[start date]* to *[finish date]*, or within 30 days thereafter. If circumstances arise that necessitate altering the duration of this partnership agreement, *[researcher]* and *[community organization]* will undergo negotiations that result in mutually agreeable terms.

This research project will be led by a Primary Researcher, *[name]*, with supervision from *[name]*. Executive Director of the *[community organization]* will aid in the investigation of this research project.

This agreement will ensure that the perspective of *[community organization]* is represented in all stages of the research project. The agreement formalizes the development of an active collaboration between the Primary Researcher and community based organization, *[community organization]*, that will ultimately apply the results from the research project.

Roles and Responsibilities

The *[community organization]* agrees to:

1. Review the draft proposal prepared by Primary Researcher including: ethics application form, informed consent form, verbal script for potential participation, safety precautions and interview guide.
2. Provide an office and telephone for Primary Researcher while working in *[location]*.
3. Assist in the initial recruitment of potential study participants.
4. Assist the Primary Researcher in contacting key community informants and arranging interviews.
5. Provide background data, such as: Regional Municipality Census, newspaper releases, names and locations of population members, previous media coverage, and anecdotal information that would contribute to the research project.
6. Participate (through consultation and feedback) in all phases of the research project to ensure that a community perspective is incorporated.

[Researcher], Primary Researcher (under academic supervision from *[name of supervisor]*) agrees to:

1. Conduct a literature review about interventions addressing *[Issue under investigation]* risk and other health issues among...
2. Conduct a document review of the...
3. Conduct ethnography...
4. Provide a final written report (including an executive summary) to *[community organization]* containing the results from items 1 through 3 above.

5. Conduct a workshop with *[community organization]* staff, board members and community partners to summarize the final report of the research project, outline recommendations and plan for application of the results at a community level.

Validation and Ownership of Research Results

Following the data analysis, the Primary Researcher agrees to present these results to the *[community organization]* in written form, in order to receive feedback from the agency. A draft of the final report is considered acceptable.

The Primary Researcher commits to writing the final report and the preliminary results of the research in a language which is clear, accessible, and easily understood. Excessive jargon and verbosity is to be avoided, and all scientific terms and concepts introduced in the documents will be clearly explained. The preliminary results will present all the elements of the project: its history, theoretical and methodological framework, the interpretation of the data, the action identified as required, as well as any proposed recommendations.

[The community organization] agrees to provide its comments and feedback within a period of 15 working days following the receipt of these preliminary results. The Primary Researcher may consider the absence of a formal response in this time period as an acceptance of the data analysis, except in the case of a written communication (letter, email, or fax) to the research team requesting an extension of the time for an agency response. Any prolongation of the time is not to exceed 15 working days. Such a prolongation for the official response of the agency can only occur one time.

According to its abilities, *[community organization]* will offer its comments in written form. In the event that the members of *[community organization]* are more at ease in giving their comments in an oral format, the organization will communicate with the Primary Researcher to formalize such an arrangement. It is understood that the same delays and timelines apply, and that the organization needs to organize itself to offer all of its comments at one time. In this case, one person will provide all of the comments of the *[community organization]* to the Primary Researcher.

The response of the *[community organization]* will identify the main points of the organization. These elements will be those most important for the agency. The *[community organization]* may also identify additional elements which are less crucial but still pertinent. The *[community organization]* will also provide its comments concerning the relevance of this research for its daily work.

The researchers agree to integrate the response of *[community organization]* in the final report. All of the major elements of *[community organization]* response will be included therein. The position of the agency as to the relevance of the research for its daily work will also be transmitted in the final report.

Following the incorporation of the comments of *[community organization]*, the primary researcher will present a draft of the final report to the agency. (This may be a second draft, if the primary researcher previously presented a preliminary version of the research to the agency.) The *[community organization]* will provide its comments concerning this version of the report within a period of 15 working days.

There may be a gap between the position of the research team and that of *[community organization]* with respect to the interpretation of the results. In this case, the gap will be noted

in the final report, as well as justification of the two positions (or of several positions, in the event that this is the situation). If the response of the agency does not offer a justification for its position, the primary researcher will solicit this essential information from the agency.

The Primary Researcher owns the raw data and is responsible for its secure storage after the completion of the research project. The audiotapes will be destroyed in one year, and the written transcripts and computer disks will be destroyed in two years.

As to the interpretation of the results, when there exists a gap between the position of the Primary Researcher and that of the agency, the Primary Researcher agrees to represent this gap, as well as the reasons which underline it, in any public discussion of the research results (media releases, conference presentation, final report, executive summary, article, book or other form of discussion).

The Primary Researcher is entitled to publication and presentation of the methods and results of the study, provided that *[community organization]* is credited as the sponsoring agency for the research project. In the event that the Primary Researcher and *[community organization]* co-author a publication or presentation, *[researcher]*, *[supervisor]*, and *[executive director of community organization]* will be stated as authors. Neither the Primary Researcher nor the agency shall publish material about the research project without permission and input from the other party.

Deliverables and Timelines:

- Draft of final research report to be presented to *[community organization]* by *[date]*, or within 30 days thereafter.
- Response by *[community organization]* to Primary Researcher within 15 working days following reception of draft of final research report.
- Completed final research report to be presented to *[community organization]* by *[date]*, or within 30 days thereafter.
- Delivery of workshop to *[community organization]* to review and apply research results within one month of final research report.

I, the undersigned, have read this agreement and agree to respect it. I am authorized to sign this agreement for my entire team.

For the research team:

For *[community organization]*:

Signature - *[researcher]*

Signature – *[executive director]*

Date

Date

Signature – *[supervisor]*

Signature - Witness

Date

Date

Source: CCPH, 2004.

Appendix C: Internet Search Results

Methods

In response to the planner's need to learn more about community-based research (CBR), RTI International (RTI) conducted a literature review and searched the Internet for information on the status of community-based research in the United States today. In this report, we identify the methods used to gather the information to develop the white paper.

Keywords used for the Internet search:

- Community participatory research
- Community-based research
- Community-based participatory research
- Participatory research
- Community research
- Community involvement
- Community involvement & research
- Community engagement
- Community engagement & research.

All of the above words were combined with "in [state name]" and then "& [state name]" for the search. Additionally, we substituted the acronym for the type of research, e.g., CBPR for community-based participatory research, CBR for community-based research.

Search Engines

- Google
- Microsoft Internet Explorer
- World Wide Web Resources for Social Workers
- EBSCO

Appendix D: Results of the Literature Review

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Community-Participatory Research

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Appendix E: Community Participatory Research Projects in the United States

To identify current CBR projects within the United States, we conducted a literature review and an Internet search on the topics of community-based research, community participatory research, community involvement, and community engagement. Our goal was to identify current CRB programs in each state, including the District of Columbia. ***Exhibit E-1*** presents the results of our search. As anticipated, we found a number of CBR projects in some states while it was difficult to identify them in others. Of the 52 states, 25 had at least 3 CBR projects, 11 had at least 2 projects, and 15 had at least 1 project. We were able to identify and list contact information, including web addresses for all of the projects. Please note that this is not an all inclusive list. However, we believe the list to be helpful when looking for states that have demonstrated the capacity to support a CBR project.

We found that the federal government has an active role in CBR. The Centers for Disease Control and Prevention has the largest number of ongoing projects (13), followed by the National Institutes of Health (6); the U.S. Department of Agriculture is partnering on 2 CBR projects. Universities constitute the remainder of the research partners conducting projects currently (7). We also found that, of the identified projects, 20 receive federal funding, 67 have state funding, and 48 have university-related funding and/or support.

Because the NCS is a noninterventional study, we also compiled a separate list (see ***Exhibit E-2***) of noninterventional CBR projects and their study reference information.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
Alabama	Five A Day for Better Health Program	Five A Day Evaluation Grants - CDC funded	National Cancer Institute, Produce for Better Health, Alabama Department of Public Health	Heidi Hattaway, M.S., RLD 334-206-5651	www.adph.org	Evaluation of the Five a Day for Health project, a comprehensive, coordinated, national nutrition program to increase the consumption of fruits and vegetables to five or more servings each day by the year 2010. Implemented at community and school levels.
	Community-Based Collaborative Research Consortium	Alabama Consortium on Forestry Education and Research	USDA Forest Service, Tuskegee Univ., Auburn Univ., Alabama A&M Univ., and Alabama Forestry Commission	John Schelhas, Tuskegee University 334-727-8131	www.cbrc.org	Research on forests and people with a focus on minority and limited landowners.
	University of Alabama, Birmingham Comprehensive Cancer Center	Deep South Network for Cancer Control	Tuskegee University, Morehouse School of Medicine	Claudia M. Hardy, Program Manager 205-975-5454	http://www3.ccc.uab.edu/show.asp?durki=59298	Research aimed at eliminating the disparity in cancer death rates between blacks and whites in the Deep South.
	The Community Outreach Partnership Center Program at Auburn University in Uniontown, AL	Uniontown 2020	Auburn University, Tuskegee University, University of Alabama, Design Corp. (nonprofit organization), and city of Uniontown	Dr. Robert Montjoy Economic Development Institute, University of Auburn Phone: 334-844-5700 Fax: 334-884-4709 montjrs@auburn.edu	http://www.auburn.edu	To help revitalize the community of Uniontown, addressing needs identified in the plan in four areas: civic infrastructure, physical infrastructure, education, and economic development. Activities include Small Business Assistance (COPC 2000) and Capacity Building for City Government.
	Gadsden State Community College Community Outreach Partnership Center Program	Family Success Center	East Gadsden community	Dr. Brenda Crowe Dean Institutional Advancement and Community Services Phone: 256-549-8228 Fax: 256-549-8444 bcrowe@gadsdenst.cc.al.us	http://www.gadsdenst.cc.al.us/index/html	To help revitalize the East Gadsden community. This includes establishing a Community Development Co, participating in and supporting the Family Services Center, helping to revitalize and beautify the urban environment, helping to improve access to affordable housing, and providing community leadership training, education assistance, employment services, services for the elderly, and training in financial skills.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
Alaska	Shaw Creek Hydraulic Monitoring and Evaluation - Environmental Baseline Study	Alaska Foreal Forest Council (ABFC - Fairbanks, Alaska)	Alaska Department of Environmental Conservation; Alaska Department of Fish & Game, Division of Sport Fish; Alaska Department of Natural Resources, Division of Forestry;	Jan Dawe, Executive Director 907-457-8453	http://www.akborealforest.org/shaw_creek/index.php	To collect the baseline environmental and hydrologic data needed to address development concerns.
	Office of Polar Programs of the NSF and Division of Elementary, Secondary, and Informal Education in the Directorate of Education and Human Resources	Teachers Experiencing the Arctic Participation with Research of Dr. Lee Cooper	Office of Polar Programs of NSF, Division of Elementary, Secondary, and Informal Education in the Directorate of Education and Human Resources, Rice University, the Cold Regions Research Engineering Laboratory, and the American Museum of Natural History	David Brown 217-223-1120	www.tea.rice.edu/index	A K-12 teacher works closely with scientists, participates in cutting-edge research, and is immersed in the process of science to increase content knowledge, enhance teaching skills, transfer the experience to the classroom and assume leadership roles.
Arizona	Southwest Interdisciplinary Research Consortium	Southwest Interdisciplinary Research Consortium	Faculty of Arizona State University	Flavio F. Marsiglia, Director 480-965-6185	www.sirc.asu.edu	Research on family and youth drug use prevention and services.
	Southwest Center for Community Health Promotion	Navajo Native American Research Center for Health (NARCH) - Student and Faculty Development Project	Inter-Tribal Council of Arizona, the University of Arizona (UA), the Hualapai Nation; & the Pascua Yaqui Tribe	Micheal Lebowitz, Director/ Principal Investigator 520-318-7270, ext. 16	http://swcchp.publichealth.arizona.edu/projects.htm#airch	Research to yield research-training opportunities to Native American students at UA and to mentor tribal nations in community-directed research projects.
	Arizona State University Community Outreach Partnership Center	Reaching Out to Neighborhoods: Communities and Universities Working Together	Morrison Institute for Public Policy, ASU faculty, city staff, & community residents	John Hall, Professor 480-965-4525	http://www.asu.edu/copp/morrison/public/reachingout.PDF	Needs assessments and research-based efforts delivered to targeted communities to address community-identified problems
Arkansas	Agricultural Research Service	Delta Nutrition Intervention Research Initiative	U.S. Department of Agriculture, Agricultural Research Service, and other Delta consortium partners	Margaret L. Bogle, ARS 501-954-9152	http://www.ars.usda.gov/is/pr/1999/990129.htm	Delta NIRI hires and trains Delta residents to survey area counties about health and nutrition problems. Scientists in the Delta NIRI program design and test nutrition interventions based on these concerns.
	Office of Chronic Disease and Disability Prevention	The Arkansas Diabetes Collaborative	Arkansas Foundation for Medical Care, Arkansas Diabetes Prevention Control Program	Dr. Fay Boozman, Director, Arkansas Department of Health 501-661-2093	www.healthyarkansas.com/services/services_diabetes.html	This collaborative includes community health centers and health education centers working together to improve diabetes care and outcomes.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
	Arkansas Department of Health	Arkansas Hometown Health Improvement	Local health departments; regional health coordinators; community stakeholders	Andrea Ridgway, 501-280-4561 Darrell Montgomery, HHI Leader 501-280-4963	http://www.healthyarkansas.com/hometownhealth/program_description.html	Collaboration and leadership in helping communities improve the health of their hometowns through coalition building, data collection/interpretation/use, information dissemination, brokering, training, community health assessment, and prioritization of health.
California	Breast Cancer Research Program	Marin County Breast Cancer Study of Adolescent Risk Factors	University of California, San Francisco, Marin Breast Cancer Watch	Walter Price, California Research Program, University of California 1-888-313-2277	www.co.marlin.ca.us/depts/HH/main/epi/research.cfm	The purpose of the study is to examine the potential relationships among established breast cancer risk factors and understudied or novel adolescent and pre-adolescent risk factors in Marin County.
	California Institute for Rural Studies	Immigration Voice Survey	Central Valley Partnership for Citizenship	Christopher Kelsch, Executive Director 530-756-6555	www.cirsinc.org	Using the survey to engage in participatory research, the Central Valley immigrant community is explored.
	Central Coast Alliance United for a Sustainable Economy	Women's Economic Project	University of Chicago, Department of Public Policy, UCLA, Department of Urban Planning	Marcos Vargas, Executive Director 504-658-0810	www.coastalliance.com	This study represents the first installment of an ongoing investigation to document and critically analyze the conditions of poverty among women in the region.
	The Community Outreach Partnership Program of California State University, Pomona	Services to Angela Chanslor area of Pomona, CA and surrounding neighborhoods	Cal Poly urban planning majors and local high school students	Dr. Aubrey Fine Director Center for Leadership and Service Learning Phone: 909-869-2799 Fax: 909-869-4747 ahfine@csupomona.edu	http://www.csupomona.edu	Activities include: COPC Learning Center, Health Care Access and Health Education, Job Development Resources and Support, Leaders-in-Training, and Livable Communities and Defensible Space.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
	The Occidental College Community Outreach Partnership Center Program	COPC	The Northeast Los Angeles Network, The Hathaway Family Resource Center and a number of community organizations called the Northeast Community Resources Coordinating Council (NECRCC)	Andrea Brown Occidental College 323-259-1407 abrown@oxy.edu	http://www.oxy.edu http://www.nelanet.org/	To work on a variety of activities aimed at revitalizing the Northeast Los Angeles area. These activities focus on surveys and major economic development, housing and home ownership, historic preservation, education, community website development, food access , environment and community greening.
Colorado	Making Connections, Denver	Baker Project	University of Denver, Regis University	Susan Motika 303-454-5369	www.makingconnectionsdenver.org	A multi-year initiative created to improve the quality of life of families living in the lower-income Denver neighborhoods.
	Center for Youth in Science, Culture and News Media	Simply the Best	University of Colorado-Boulder Outreach Committee	Dr. Margaret Eisenhart, Director, School of Education, University of Colorado-Boulder 303-492-8583	www.colorado.edu/education/cy.scan/index.html	Community based after-school technology and science instruction program.
	Family and Youth Institute	Community Organizing to Reach Empowerment (CORE) Center	Colorado State University College of Human Sciences; Colorado State University Cooperative Extension	Marilyn Thayer, Co-Director 970-484-2580	http://www.cahs.colostate.edu/fyi/ProgramsProjects/OtherProgramsCORE.htm	Research project to provide opportunities for community residents to build on their strengths and develop their capacity for addressing perennial urban problems.
	The Community Outreach Partnership Center Program of the University of Colorado, Denver	The Westside Outreach Center	NEWSSED, a nonprofit organization	Tony Robinson Colorado Center for Community Development 303-352-0299 Tony.Robinson@cudenver.edu	http://www.carbon.cudenver.edu http://www.cudenver.edu/westside/	Working to increase the amount of quality affordable housing in Westside, to provide increased education and employment opportunities to residents, to offer tenant and homeowner education that will reduce fair housing and tenant law violations, and to facilitate community organizing, leadership development, and planning activities.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
Connecticut	Hispanic Health Council	Building Community Responses to Risks and Emergent Drug Use in Hartford, Connecticut	Connecticut Department of Health	Jeannette B. De Jesus, Executive Director 860-527-0856	www.hispanichealth.com	A research project to develop new methods for enhanced surveillance and community response to emergent drug use.
	Yale University, Center for Interdisc. Research on AIDS	Sexual Acquisition and Transmission of HIV Cooperation Agreement Program	Hispanic Health Council, The Institute for Community Research	Leif Mitchell, CPG Co-Chair, Community Research Core Coordinator 203-764-4333	http://cira.med.yale.edu/index.html	Basic social and behavioral research aimed at identifying the determinants of HIV-related risk in different vulnerable populations. Several of these projects combine social/behavioral with biomedical/laboratory research in innovative ways
	Housatonic Community College (HCC) Community Outreach Partnership Center.	Building Organizational and Community Capacity	The Communities of Bridgeport and Lower Naugatuc Valley Area of Connecticut.	Dr. Robert Thornton, Dean Outreach Services, Housatonic Community College, 900 Lafayette Blvd., Bridgeport CT, 06604. Phone: (203)3325084.	http://www.hcc.comnet.edu	Building organizational and community capacity, Health Care Outreach, and affordable, fair housing.
	Yale Griffin Prevention Research Center	Smoking Cessation/Prevention	State and local health districts, a local school district, faith based organizations, school-based and primary care health clinics, Griffin Hospital, the Valley Council, the local United Way, The New Haven Foundation, the Valley YMCA, Yale faculty	Michael H. Merson, MD, Principal Investigator, 203-785-2867; David Katz, MD, MPH, Center Director 203-732-1265	www.yalegriffinprc.org	An evaluation of smoking cessation intervention targeted and adapted for various populations and settings.
	The Community Outreach Partnership Center Program of Housatonic Community College	HCC's Community Outreach Partnership Center	Bridgeport	Dr. Robert Thornton, Dean Outreach Services Phone: 203-332-5084 Fax: 203-332-5123 ho_rthornton@commnet.edu	http://www.hcc.comnet.edu	HCC's COPC activities for inner-city Bridgeport include organizational and community capacity-building; a standardized training program for community health advisors; dissemination of information on financial literacy and affordable, fair housing; family literacy programs; accreditation for child care providers, and child development associates certification; and multimedia resources for publicizing COPC activities.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
Delaware	Delaware Child Welfare Demonstration Waiver	Services to Substance-Abusing Caretakers - Delaware	Delaware Department of Health and Human Services - Department of Family Services; local Substance Abuse Counselors; local Children's Protective Service workers	Candace Chodorow, DDHSS 302-633-2601	www.researchforum.org/project_abstract_205.html	An evaluation of a program that includes providing substance abuse counselors to work with CPS staff and identified families at risk of having children placed in foster care due to parents' substance abuse.
	Wilmington Housing Authority	HOPE VI Initiative in Northeast Wilmington	Delaware State University; U.S. Dept. of Housing and Urban Development; Head Start; Center for Human Development; WHA, Leon N. Weiner & Associates; state and local government; private businesses and nonprofit organizations	Archbishop Walsh Holmes, HOPE VI Coordinator, 302-429-6701 ext. 22	http://www.whadelaware.org/hopevi.html	Initiative working with community stakeholders to revitalize neighborhoods based upon community needs assessments and recommendations, including physical improvements, management improvements, and social and community services to address resident needs
	Kids Count	Kids Count in Delaware	University of Delaware's Center for Community Research and Service; Families Count Initiative; Annie E. Casey Foundation	Terry Schooley 302-831-4966	www.dekidscount.org	Project utilizes Kids Count indicators as a baseline for discussion and further inquiry with community stakeholders regarding the needs of children in the state.
District of Columbia	Community Research and Learning Network	Columbia Heights Action Research Project	Community Research and Learning Network, Project South	Sam Marullo, Founder 202-371-9170	www.coralnetwork.org	This project seeks to analyze the impact of urban redevelopment and gentrification on this low-income neighborhood.
	District Community Voices Organized and Informed for Change in Education	Half the Solution: The Supports D.C. Students Need to Meet High Academic Standards	Poverty and Race Research Action Council	Carmella Mazzotta, Executive Director 202-986-8535	www.dcvoice.org	A project to engage parents, teachers, students and the community members in dialogue about educational standards and the supports needed to achieve them.
	The Georgetown University Center for Outreach and Community Partnership	Empowerment Zones: North Capitol and Mt. Pleasant/Columbia Heights of the District of Columbia.	Faculty from six Georgetown colleges working with community residents and leaders from more than 15 community-based organizations.	Dr. Jeff Collman, Box 57 1037 597, Washington, DC, 20057; Phone: (202)784-3433 Collman@isis.imac.georgetown.edu	http://georgetown.edu	COPC activities focus on enhancing planning and community organization, reducing violence and crime among adolescents.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
	Georgetown University's Center for Social Justice Research, Teaching & Service	Partners in Urban Research and Service-learning	Bates St City Assoc; Sursum Corda Housing; Cardozo High School; Northwest Cooperative; Neighborhood residents; Latin American Econ Dev Corp; Mary's Center; Council Latino Agencies; Asian American Leads; Georgetown School of Medicine; School of Nursing	Kathleen Maas Weigert, Ph.D., Director 202-687-5330	https://data.georgetown.edu/ou/teach/csj/research/purs/index.html	Community and university participants worked collaboratively to define research questions, create research designs, oversee grant writing and implement research projects, including organizing and sponsoring a pilot research project on youth violence and urban redevelopment.
Florida	Jacksonville Community Council, Inc.	Jacksonville Public Services: Meeting Neighborhood Needs	University of Florida	David Swain, Associate Director, Jacksonville Community Council, Inc. (904) 396-3052	http://www.jcci.org/newerhome.htm	A community participatory project to assess the fairness of public service distribution in Jacksonville.
	Florida Department of Health - The Florida Diabetes and Prevention Control Program	Reducing Racial and Ethnic Health Disparities: Closing the Gap; individual committees for the 6 community-based projects	The Racial and Ethnic Health Disparities Advisory Committee	Betty L. Smith 850-245-4002	http://www.doh.state.fl.us/equopp/ctg/indexctg.html	An initiative that works to eliminate racial and ethnic health disparities in Florida.
Georgia	Institute of Public Health, Georgia State University	Georgia Tobacco Policy Project	American Legacy Foundation, Faculty of GSU Colleges	Dr. Jan Jernigan, Institute of Public Health, Georgia State University 404-463-0215	publichealth.gsu.edu	An initiative to promote and secure the implementation of effective tobacco control policies.
	Project South	Following the Money in Georgia Politics	Center for Responsive Politics; grassroots community members; academic activists	Abbie Ellenberger, Project South 404-622-0602	www.projectsouth.org	A research study investigating the influence of money on Georgia politics.
	Mercer Center for Community Development	The Community Outreach Partnership Center at Macon University	Mercer County Community Development (MCCD)	Dr. Peter Brown, Mercer Center for Community Development, 1400 Coleman Avenue, Macon GA, 31207, (912)301-5370	http://www.mercer.edu	Designed to serve as a demonstration model to initiate revitalization and community development in other Macon neighborhoods.
	Southeast Community Research Center	Tools for Change	Albany State University	Douglas Taylor Executive Director 404-373-6688	www.cbpr.org	A statewide project which focuses on the African-American and Latino communities and the negative effects of the disparities in health outcomes and treatment.

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State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
Hawaii	Hawaii Island Rural Health Center	Effects of Volcanic Air Pollution on Respiratory Health	John A. Burns School of Medicine, Harvard School of Public Health	Elizabeth K. Tam, Principal Investigator 808-956-8120	http://www.ruralhealth.hawaii.edu/hawaii.htm	Initiative to engage residents of the Big Island of Hawaii in research that explores the effects of volcanic air pollution ("vog") on their respiratory health
	The Native Hawaiian Cancer Research and Training Network	Imi Hale	National Cancer Institute	Clayton Chong, M.D., Papa Ola LokaHi 808-597-6550	http://imihale.org/	Project that seeks to launch culturally appropriate research activities aimed at all aspects of Native Hawaiian cancer issues.
Idaho	Henry's Fork Watershed Center	Henry's Fork Watershed Council	U.S. Bureau of Reclamation, Idaho Department of Water Sources	Susan Steinman 208-652-3567	www.henrysfork.com	Fish, wildlife and irrigation issues are the subject of this project.
	Life's End Institute	Missoula Demonstration Project	Rallying Points	Lilly Tuholske 877-257-9970	lifes-end.org	Initiative to demonstrate a community-based approach of excellent physical, psychosocial, and spiritual care for dying persons and their families.
Illinois	Midwest Latino Health Research Training and Policy Center	Health Quality Program	University of Illinois at Chicago, Jane Addams College of Social Work	Aida L. Giachello, Ph.D., Center Director 312-413-1952	http://www.uic.edu/jaddams/mlhrc	The project has the long-term goals of improving the health status and the quality of health care delivery to Hispanics/Latinos in Chicago and throughout the Midwest region using a community participatory research model.
	PRAG - Policy Research Action Group	Greater West Town Community Development Project	Community-based nonprofit organizations; Chicago State University; DePaul University; Loyola University; University of Chicago; National-Louis University; University of Illinois – Chicago	Bill Leavy, Executive Director 312-432-1300	www.gwtp.org	The project seeks to build a community-based collaborative response to the problems of unemployment and limited educational opportunities for disadvantaged residents of 3 neighborhoods.
	Southern Illinois University Carbondale's (SIUC's) Community Outreach Partnership Center	North Carbondale (NC)	The North Carbondale Citizens Advisory Committee, the Attucks Community Service Board	Dr. Tess Heiple, Center for Rural Health and Social Service Development, Illinois University, Carbondale, IL 62901. Phone (618)453-1732	http://www.siu.edu/siuc/	Affordable Housing Program, Education Assistance Program, Health Services Program, Neighborhood Revitalization Program.

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	The Loyola University Chicago's Center for Urban Research and Learning.	Rogers Park	Loyola University Chicago, Rogers Park Community	Dr. Philip Nyden, Center for Urban Research and Learning, 820 N. Michigan Ave. , Chicago IL, 60611. Phone: (312)915-7761	http://www.luc.edu/depts/curl	Increased access to quality childcare, Preserving Affordable Housing, Preserving and developing small businesses
	University of Chicago Community Outreach Partnership Center Program.	Woodlam Community Partnership Program	Chicago Housing Authority, the South East Chicago Commission, the Illinois Department of Children and Family Services.	Henry Webber, University of Chicago, 969 East 60 th Street, Chicago IL, 60637. Phone: (773)702-3627	http://www.uchicago.edu	Provide technical assistance for community's infrastructure, improve educational opportunities, facilitate positive community interaction.
	College of Fine and Applied Arts - University of Illinois at Urbana-Champaign	East St. Louis Action Research Project	Faculty and staff from various departments at University of Illinois at Urbana-Champaign and other campuses; neighborhood representatives	Vicki Eddings, Administrative Coordinator 217-265-0202	http://www.eslarp.uiuc.edu/	Project in which faculty and students from several campus units collaborate with each other and East St. Louis neighborhood groups on highly tangible and visible projects that address the immediate and long-term needs of some of the city's most distressed neighborhoods.
Indiana	Indiana University, Northwest (IUN) Community Partnership Outreach Center	Gary, Hammond and East Chicago Communities.	IUN and the City of Gary, IN	Dan Lowery, Indiana University, Northwest - SPEA, 3400 Broadway, Gary IN, 46408	http://www.indiana.edu/campus/iu-northwest.htm	The COPC is focusing on 4 outreach activities directed towards urban problems of education, neighborhood revitalization community organization, and economic development.
	The Community Outreach Partnership Center at Butler University in Indianapolis.	Butler-Tarkington Neighborhood	The Martin Luther King Multi-Service Center, the Butler-Tarkington Neighborhood Association	Dr. Margaret Brabant, 4600 Sunset Avenue, Indianapolis IN, 46208. Phone: (317)940-9683	http://www.butler.edu	Neighborhood Revitalization, Crime prevention and housing.
	Ball State University Community Outreach Partnership Center	Consolidated Plan for the City of Muncie	City of Muncie, Ball State University, and other local agencies	Mr. Eric Kelly, 2000 University Avenue, Muncie IN 47306. Phone: (765)285-1963	http://www.bsu.edu	Neighborhood support, homeless programs, employment opportunities, core revitalization programs, and citizen education and leadership training.
	Valparaiso University Community Outreach Partnership Center	The Hilltop Neighborhood of Valparaiso	Union Community Church, Casa Centrale, the Hilltop Neighborhood Association	Dr. Larry Baas, Dept. of Political Science, Valparaiso IN, 46383. Phone: (219)464-5266	http://www.valpo.edu/organization.copc/ind ex.htm	Affordable housing support and Mentoring programs for the youths.

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	The Institute of Action Research for Community Health	Healthy Cities Indiana	Indiana University-Purdue University; World Health Organization	Dr. Beverly Flynn, Director 317-274-3319	http://www.iupui.edu/~citynet/cnet.html	Project that uses action research to provide information that will encourage communities to build a safe and healthy environment within urban areas.
Iowa	Children's Environmental Health and Disease Prevention Research	The Etiology and Pathogenesis of Airway Disease in Children from Rural Communities	University of Iowa	David Schwartz, Principal Investigator, University of Iowa 319-335-3500	www.medicine.uiowa.edu	The theme of the initiative, to investigate the etiology and pathogenesis of airway disease in children from rural communities.
	The Community Outreach Partnership Center at Iowa State University (ISU)	The Enterprise Community (EC) of Des Moines, Iowa.	Iowa State University, Des Moines City Council EC and its 5 Neighborhoods	Dr. Riad Mahayni, Dept. of Community and Regional Planning, 126 College of Design, Ames IA, 50011. Phone: (515)294-8958	http://www.public.iastate.edu/	Neighborhood Revitalization, Affordable Housing, Home Improvement Project, and Money management Workshop.
	The University of Northern Iowa Community Outreach Partnership Center	Consolidated Urban Revitalization Area, (CURA) Waterloo	University of Northern Iowa, Public and Private entities of the City of Waterloo, IA	R. Hays, 1227 West 27 th Street, Cedar Falls IA, 50614. Phone: (319)273-2910	http://www.uni.edu	Enhancing the human and social capital of the area.
	Division of Extramural Research and Training	Rural Childhood Asthma Study - Louisa Environmental Intervention Project	University of Iowa College of Public Health	Peter S. Thorne, Principal Investigator, University of Iowa College of Public Health 319-335-4415	www.public-health.uiowa.edu	This is an environmental intervention study of asthmatic children who reside in a rural, medically-underserved and ethnically diverse county.
Kansas	University of Kansas School of Medicine	Fitness Task Force	Kansas Area United Methodist Fitness Task Force; United Methodist Health Ministry Fund	Judy Johnston, MS, RD/LD, Research Instructor 316-293-1861	http://www.healthfund.org/ind/ex.php	A collaborative planning and implementation with a medical school and the United Methodist Churches of Kansas to promote healthier lifestyles among United Methodist Church clergy and parishioners.
Kentucky	University of Kentucky Community Outreach Partnership Center	The East End Community Outreach Partnership	The University of Kentucky, the Lexington Fayette Urban County Government, and 24 local community organizational, and local citizens	Dr. Retia Walker, Dean College of Human Environmental Sciences, University of Kentucky, 102 Erikson Hall, Lexington KY, 40506. Phone: (859)257-4095	http://www.uky.edu	Revitalize the East End Community, including identifying needs for community and self sufficiency, better educational attainment, affordable and habitable housing.

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State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
	University of Louisville Community Outreach Partnership Center	Louisville Enterprise Community (10 neighborhoods)	The Neighborhood Development Corporation, the Canaan Community Development Corporation, Neighborhood Housing Services, Louisville Central Development Corporation, the Louisville Department of Economic Development, and local banks	Dr. John Gilderbloom, Center for Sustainable Urban Neighborhoods, Belknap Campus, 426 West Bloom Street, Louisville KY, 40208. Phone: (502)852-8557	http://www.louisville.edu/org/	
	Highlander Research and Education Center	Investigating Illegal Disposal of Toxic Wastes in Yellow Creek, Kentucky	Yellow Creek Concerned Citizens of Kentucky	Jim Sessions, Director 423-933-3443	www.highlandercenter.org	A project examing the negligent disposal of hazardous chemicals.
Louisiana	Louisiana State University Community Outreach Partnership	The Community- University Partnership (CUP)	Fannie Mae, the Young Leader' Academy of Baton Rouge, Inc, Baton Rouge Green, Louis A. Martinet Legal Society, the Dr. Leo S. Butler Community Center, the Baton Rouge Housing Authority, the Baton Rouge Area Foundation, Volunteer Baton Route, and Fort Worthing.	Dr. Gregory Vincent, Vice Provost, Academic Affairs, Louisiana State University, 146 Thomas Boyd, Baton Rouge LA, 70803. Phone: (225)578-5739	http://www.lsu.edu	Community Beautification, Community Revitalization, Helping At-Risk and Troubled Youth, Playground and Park Development, Technical Assistance to Nonprofit Organizations, Revitalizing a Commercial Corridor of Old South Baton Rouge (OSBR).
	Louisiana Diabetes Prevention Control Program	Project Assist	City of New Orleans Health Department's Healthcare for the Homeless Clinic	Shawn Smith, MSW 504-568-7210	http://oph.dhh.state.la.us/chronicdisease/diabetes/pagebdf9.html?page=52	The mission of the Louisiana Office of Public Health Diabetes Control Program (DCP) is to reduce the morbidity and mortality of diabetes in the state of Louisiana.
Maine	University of Maine Center for Community Inclusion and Disability Studies	Maine Adolescent Transition Partnership	Maine Department of Human Services, Bureau of Health, Coordinated Care for Children with Special Health Care Needs and the Center for Community Inclusion and Disability Studies, UAP, University of Maine	Elizabeth DePoy 207-581-1469	http://www.umaine.edu/ci/maip/index.html	A project to develop a statewide collaborative program that will enhance the transition of adolescents with special health care needs from high school to work and/or higher education.

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Maryland	University of Maryland, Baltimore Community Outreach Partnership Center.	The West Baltimore Empowerment Initiative.	University of Baltimore, MD., Four village centers in the West Baltimore Empowerment Zone (EZ). adjacent to UMB Campus	Dr. Richard Cook, School of Social Work, 525 West Redwood Street, First Floor, Baltimore MD, 21201. Phone: (410)706-4455.	http://www.umaryland.edu	Provide training in leadership development, community problem solving, and community mapping; create job readiness programs and form community development corporations.
	Maryland Diabetes Prevention and Control Program	Diabetes Prevention and Control Coalition	Department of Health and Mental Hygiene, CDC, local health departments	Earl Shurman 410-767-6788	http://www.fha.state.md.us/oc/d/diabetes/index.html	This broad-based coalition of key stakeholder organizations works in close partnership with the Maryland DPCP to plan, implement and evaluate diabetes prevention and control activities that are science based and data driven.
	University of Maryland	Family Policy Impact Seminar	Maryland Cooperative Extension, University of Maryland Department of Family Studies, National Family Policy Impact Seminars	Bonnie Braun, PhD, Associate Professor 301-405-3581	http://www.hhp.umd.edu/FMS/T/fis/	The University of Maryland Family Policy Impact Seminar has been actively seeking to engage populations that are low-income, recent immigrants, youth or other voices that are often overlooked during the policy-making process.
Massachusetts	Fitchburg State College Community Outreach Partnership Center.	Fitchburg State College Community Outreach Partnership Project.	Community Advisory Committee, Fitchburg State College, Local Government.	David Newton, 160 Pearl Street, Fitchburg MA 01420, Phone: (978)665-3574.	http://Falcon.fsc.edu	Need assessment surveys, Data analysis of community health needs, Research and analysis of present micro-enterprise development in Cleghorn and citywide, sustainable affordable housing.
	JSI Center for Environmental Studies	Woburn Childhood Leukemia Study	Harvard School of Public Health, Massachusetts Department of Public Health	Mary Firestone 617-482-9486	www.envirolink.org	Community research to examine the correlation between outbreaks of childhood leukemia and exposure to water from wells.

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Michigan	Eastern Michigan University Community Outreach Partnership Center.	Ypsilanti, Community Outreach Partnership Project.	The City of Ypsilanti, Gateway Community and Economic Development, JOSHUA, Inc., Michigan Small Business Development Center, SOS Community Services, Organization of Latino Social Workers, Washtenaw Community College, Ypsilanti Township Economic Development Office.	Dr. Elvia Krajewski-Jaime, COPC Director, Department of Social Work, Eastern Michigan University, 203 Boone Hall, Ypsilanti MI, 48197. Phone: (734)487-0284.	Http://www.emich.edu	Community building and civic engagement, education and youth leadership, economic development and employment.
	Western Michigan University Community Outreach Partnership Center.	Benton Harbor Community Outreach Program.	City of Benton Harbor,, The Black Chamber of Commerce, The Lake Michigan Community College Small Business Development Center, Benton Harbor Area Schools, Berrien County Health Department,, United Way of Southwest Michigan.	Ms. Sharon Anderson, Western Michigan University, Wallwood Hall, Kalamazoo MI, 49008. Phone: (616)387-8873.	http://www.wmich.edu	Enable Benton Harbor residents to define, reframe, and actively pursue their community's future.
	Calvin College Community Outreach Partnership Program Center.	The Garfield Park Neighborhoods Association (GPNA)	The Burton Heights Business Association, Calvin College, and various non-profit organizations.	Dr. Steven Timmermans, Calvin College, 3201 Burton Street SE, Grand Rapids MI, 49546. Phone: (616)957-6577	http://www.calvin.edu	Addressing the health needs of the Burton Heights residents, Community revitalization for the Burton Heights neighborhood, Expanding educational opportunities for the Burton Heights residents.
	Michigan Center for the Environment and Children's Health	Community Action Against Asthma	Community Health and Social Services Center, Detroit Hispanic Development Corporation	Katherine Edgren, Project Manager 734-615-0494	www.sph.umich.edu/mcech	Research combining an investigation of environmental triggers of asthma with an intervention designed to reduce exposure to these triggers and improve the health status of children with asthma.
	The Family Development Project	The Family Development Project	Detroit Public Schools Head Start, University of Michigan	Michael Spencer, Assistant Professor 734-764-7224	www.cbrc.org/php-bin/members/memberlist.php?id=366	A research and service learning collaborative aiming to develop mental health services for children and families in Detroit's Head Start.
	Michigan Diabetes Prevention and Control Program	Michigan Diabetes Outreach Network	CDC, local health departments, University of Michigan, Michigan Diabetes Research and Training Center	Diabetes Control and Prevention Program Coordinator- 517-335-8445	http://www.cdc.gov/diabetes/states/mi.htm	Diabetes prevention program that collects research within the community to determine whether care of diabetic clients has improved over time due to the project's objectives.

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Minnesota	Minnesota Parenting Association	The Council for Parent Leadership	Children Youth and Family Consortium, University of Minnesota Extension Service , College of Human Ecology	Roxy Foster, Civic Organizing Partners 651-290-4755	http://parentleadership.org/	Development by a community organization of an online resource for parents interested in developing their civic leadership skills.
	Diverse Racial Ethnic Groups and Nations (DREGAN) Project	Tobacco Use Reduction Program	Minnesota Partnership for Action Against Tobacco, Blue Cross & Blue Shield of Minnesota	Dr. Steven S. Foldes, Co-Director 651-224-0170	http://nctb.confex.com/nctb/2002/techprogram/paper_6719.htm	Project to reduce tobacco use in Minnesota's communities of color through the use of community research on cultural attitudes towards tobacco use.
	University of Minnesota's National Teen Pregnancy Prevention Research Center	Primetime	CDC, University of Minnesota, local teen pregnancy clinics	Michael Resnick, Ph.D 612-624-9111	http://www.cdc.gov/prc/centers/minnesota.htm	A youth-development strategy for preventing teen pregnancy.
	University of Minnesota Community Outreach Partnership Program	The East Side Community Outreach Partnership Center	Macalester College, Metropolitan State University, East Side Neighborhood Development Corporation, Dayton's Bluff Neighborhood Housing, The Local Initiatives Support Corporation, the American Indian Center, The Minnesota Campus Compact, Dayton's Bluff Community Council, the Payne-Phalen Community Council	Mr. Frederick Smith Coordinator Center for Urban and Regional Affairs Phone: 612-625-0508 Fax: 612-626-0273 smith009@maroon.tc.umn.edu	http://www.umn.edu http://www.npcr.org/index.html	The East Side COPC has three main goals: to obtain and maintain an adequate supply of safe, decent, affordable houses, to provide an adequate number of jobs that pay livable wages, and to provide residents with resources necessary to secure well-paying jobs in the neighborhood.
Mississippi	Office of Urban Affairs	Mississippi Delta Project	National Institutes of Health, Office of Solid Waste and Emergency Response	Reuben C. Warren, Associate Administrator 404-498-0117	atsdr.cdc.gov	Focusing on persons in underserved communities the project's goal is to promote environmental quality.
	Missouri Action Research Connection (MARC)	Rural Coalition Supermarket Empowerment Evaluation	Rural Coalition Supermarket leaders	Dr. Sandy Rikoon 573-882-0861	www.missouri.edu/~moaction/projects	Program aimed at conducting a member self-evaluation of the cooperative marketing project. Community members served as an evaluation team.

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Missouri	Missouri Diabetes Prevention and Control Program	Diabetes Today	CDC, community leaders and concerned citizens	Diabetes Prevention and Control Program Coordinator 1-800-316-0935	http://www.health.state.mo.us/diabetes/	The MDPCP trains local community leaders and concerned citizens to identify needs and resources for individuals with diabetes and their family members and assists these coalitions in planning, implementing and evaluating community-level programs to prevent and control diabetes and its complications.
	Missouri Action Research Connection (MARC)	Sedalia Community Free Clinic	Missouri Institute for Community Health Advisory Council, Community Free Standing Clinic	Dr. Sandy Rikoon 573-882-0861	http://www.missouri.edu/~moaction/projects	The Community Free Clinic provides medical care to uninsured, underinsured and Medicaid-covered population in the Sedalia area; demographic data on clinic's target population is compiled and used to seek external funds.
	University of Missouri – St. Louis Community Outreach Partnership Center Program	The Old North St. Louis Neighborhood COPC	Old North St. Louis Restoration Group, Gateway to Financial Fitness, Parent Link, City of St. Louis Health Department, St. Louis Lead Prevention Coalition, Missouri Historical Society and Grace Hill Neighborhood Services	Kay Gasen, Director Community and Neighborhood Development Phone: 314-516-5273 Fax: 314-516-5268 gasen@umsl.edu	http://www.umsl.edu	To support revitalization efforts in the Old North St. Louis Neighborhood. Among the goals of the COPC are to develop a strong base for the community by training community leaders and facilitating an assessment of community assets and resources, offer home maintenance and financial literacy assistance for low-and moderate-income residents, develop community-based health prevention strategies, and assist residents in neighborhood stabilization and historical preservation

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Montana	Intermountain Forest Industry Association	Flathead Common Ground	Weyerhaeuser Corporation, Montanans for Multiple Use	Greg Schildwachter 406-542-1220	http://www.iffia.com/	Wildlife protection is the focal point of this project.
	University of Nebraska-Lincoln	Technology accessibility project	Community and Regional Planning Department at UNL, GIS Workshop, city of Lincoln's 4 minority cultural centers	Rodrigo Cantarero 402-472-9278	http://archweb.unl.edu/crp/	The project is a pilot to test the ability to make GIS information and technology accessible to small community organizations throughout the city.
Nebraska	University of Nebraska-Lincoln Community Outreach Partnership Center Program	University of Nebraska-Lincoln COPC	The Cooper Foundation, the Foundation for Educational Funding, Inc., Woods Charitable Foundation, LINC Grant, Hispanic Community Center, Asian Community Center, Clyde Malone Community Center, and the Indian Center.	Dr. Robert Drummond, Dean College of Architecture 402-472-3806 wdrummond@unl.edu	http://www.unl.edu	To address a wide variety of problems in the City of Lincoln including inadequate housing, high school dropout rates, high rates of morbidity, and isolation within the community, the UNL COPC will offer a centralized location for community development activities to benefit ten needy neighborhoods and will focus on specific issues related to housing, community involvement and the region's youth.
	Childhood Cancer Research Institute	Managing Radiation Contamination Risks in Native American Communities	Clark University, local tribal groups	Dianne Quigley, Executive Director 508-751-4615	http://www.cehn.org/cehn/resourceguide/ccri.html	The program sought to develop a community-based infrastructure that would enable the communities to develop and disseminate accessible information on nuclear contamination health hazards and create a community-based hazards management plan.
Nevada	Clark University	Community-Based Hazard Management Program	CDC, National Center for Environmental Health	Octavia Taylor, Executive Director 508-793-7711	http://www.clarku.edu/departments/marsh/projects/community/index.shtml	Community-Based Hazard Management is a non-profit research and education organization dedicated to capacity building in communities affected by the production and testing of nuclear weapons.

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	Suicide Prevention Resource Center	Suicide prevention programs	CDC, American Association of Suicidology (AAS), American Foundation for Suicide Prevention (AFSP), local community interest groups	Lloyd Potter, Center Director 617-618-2314	http://www.sprc.org	This is a program aimed at preventing suicide in NV, a state with one of the highest suicide rates in the country.
New Hampshire	New Hampshire Real Choice Systems Change	Littleton Model Community Project	Institute of Disability	Alexandra Evans, Project Manager 603-228-2084	www.realchoicenh.org	The Littleton community's perception of the elderly and individuals with disabilities is explored.
	University of New Hampshire Cooperative Extension	Teen Assessment Program	University of New Hampshire Cooperative Extension, Pemi-Baker School District	John Pike, Director 603-862-1585	ceinfo.unh.edu	A comprehensive survey-based study exploring youth.
	New Hampshire Lakes Lay Monitoring Program	Fish Condition Study	University of New Hampshire,	Jeff Schloss, Coordinator 603-862-3848	http://www.uwex.edu/ces/csresvolmon/RelatedResearch/NHParticipatoryResearch.html	A program which used community members to gather data regarding pollution in fisheries.
New Jersey	New Jersey Health Initiatives	Trenton Childhood Asthma Project	Rider University	Patricia Nelson-Johnson, Coordinator 609-989-3636	www.nijhi.org	Study assesses the prevalence and severity of pediatric asthma in Trenton.
	Rutgers University	Survey of Camden Children's Health Needs	Camden AHEC, Johnson & Johnson Family of Companies	Dr. Bill Whitlow 856-225-6741	http://children.camden.rutgers.edu/ResearchProjects/Whitlow_HealthNeeds.htm	Needs assessment to determine community concerns surrounding children's health.
	The College of New Jersey	Trenton Youth Community-Based Research Corps	Bonner Foundation, Trenton Youth Services Commission, Trenton Center for Campus-Community Partnerships, AmeriCorps	Beth Paul 609-771-2651	http://www.bonner.org/pdf/bestpractices/TCNJ_Research_Corps.pdf	This program assists students in conducting community-based research grounded in close working relationships with community leaders and provides community organizations with research results and engages them in authentic partnership with the College.

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	Rowan University Community Outreach Partnership Center Program	Rowan University COPC in Camden, NJ	City of Camden, the Camden Board of Education, the Camden Empowerment Zone(EZ),and several area healthcare providers	Mr. Jerome Harris Executive Director Urban & Public Policy Institute 856-256-4500, Ext. 3176 harrisJ@rowan.edu	http://www.rowan.edu	The Rowan University COPC is complementing the community economic revitalization efforts of Camden, NJ including the Ford Foundation Community Development Partnership Initiative and designation as a Federal Empowerment Zone by providing selected groups in four neighborhoods with capacity building and strategic planning assistance. It is also expanding local early- childhood services, targeting job development, training, and placement services to welfare- to-work population and improving the area's economic development infrastructure.
	New Jersey City University Community Outreach Partnership Center Program	COPC BUILDS	City of Jersey City, the Jersey City Housing Authority, St. Peter's College, and the Jersey City Police Department	Dr. Jill Lewis Phone: 201-200-3325 Fax: 201-200-3312 jlewis@njcu.edu	http://www.njcu.edu	COPC Builds will focus its activities in areas that will help neighborhood residents rebuild their community including crime prevention, economic development, and infrastructure improvements.
	Montclair State University Community Outreach Partnership Center Program	Montclair State University COPC	Montclair University's College of Education and Human Services, the Township of Montclair, Home of Montclair Ecumenical Corporation (HOME Corp.), Day Nurseries, Montclair Neighborhood Development Corporation, The Montclair State Foundation, the Center for Community-Based Learning and the Institute for Community Studies.	Dr. Freyda Lazarus Director Center for Community-Based Learning Phone: 973-655-7553 Fax: 973-655-5150 lazarusf@mail.montclair.edu	http://www.montclair.edu	The COPC was established to improve residents' capacity to work together in addressing the needs of the neighborhoods through community organizing activities, promote neighborhood stability and affordable housing through a series of workshops, provide activities for youth , and develop a multigenerational program to help residents learn to use computers

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	Rutgers University Community Outreach Partnership Center Program	RCOPC in Newark's West Side Park Community	Newark Neighborhood Empowerment Council, Newark Community Development Network, Corinthian Housing Development Corporation, International Youth Organization and other community-based organizations.	Dr. Robert Lake Assistant Director Center for Urban Policy Research Phone: 732-932-3133, Ext. 521 Fax: 732-932-2363 rlake@rci.rutgers.edu	http://www.rutgers.edu	RCOPC is linking directly to ongoing efforts to spur Newark's revitalization through a comprehensive, multidisciplinary strategy to support neighborhood renewal. The COPC provides planning assistance, capacity building, skills and leadership training, job development, and direct services in housing, health care, economic development, and education to further the revitalization of the West Side Park community.
New Mexico	Community Programs for Clinical Research on AIDS	Partners in Research: New Mexico Unit # 022	Centers for Disease Control and Prevention, National Institutes of Health, U.S.Department of Defense	Bruce Williams, M.D., Principal Investigator, Partners in Research 301-628-3000	www.cpcra.org	This is a clinical trials program with a focus on HIV disease and AIDS.
	Division of Extramural Research and Training	A Social Network-Based Intervention to Reduce Lead Exposure Among Native American Children	Emory University, University of Oklahoma Health Sciences Center	Michelle Kegler, Principal Investigator, Emory School of Health 404-712-9957	www.emory.edu	A Native American community is mobilized to address childhood lead poisoning in rural area contaminated with mine waste.
New York	Division of Extramural Research and Training	Asthma Intervention in New York City	Columbia University	Patrick L. Kinney, Associate Professor, Columbia University 212-305-3663	www.columbia.edu	The effects of allergens and air pollutants on asthma incidence in inner-city children.
	The Graduate Center	The Harlem Birth Right Project	The Graduate Center	Dr. Leith Mullings 212-817-7000	www.gc.cuny.edu	Examining the social forces that impact racial disparities in health as they impact pregnancy outcomes of women in Harlem.
	New York Diabetes Prevention and Control System	Diabetes Prevention Program	CDC, Harlem Prevention Center, Einstein Diabetes Research and Training Center	Program Coordinator 518-474-1222	http://www.cdc.gov/diabetes/sites/ny.htm	Program to research and prevent diabetes.
	Rensselaer Polytechnic Institute	The community Outreach Partnership Center Program	Local community, RTI's Planning and Facilities Design and other departments	Dr. Ron Eglash, Assistant Professor, Rensselaer Polytechnic Institute 518-276-2048	http://www.rpi.edu	The activities of the center are aimed at enhancing livability, development, and infrastructure in three neighborhoods adjacent to RPI campus.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
	State University of New York at Cortland Community Outreach Partnership Program	SUNY Cortland COPC in Cortland	City of Cortland, One-Stop Care Center, RAC	Dr. Craig Little Department of Sociology/Anthropology 607-753-2470 LITTLE@snycorva.Cortland.edu	http://www.cortland.edu	The COPC is located at the One-Stop Care Center and will focus on issues of urban planning, crime prevention, economic development, job training, education, and housing.
	Cornell University Community Outreach Partnership Center Program	Cornell University COPC targeting the Ithaca Flats Neighborhoods of Southside, Northside, Downtown and Titus Flats	Ithaca City Planning Department, the Housing Authority, the Urban Renewal Agency, the Ithaca Public Schools, the city police department, the Economic Opportunity Corporation, Catholic Charities, and the Southside Community Center	Patricia Pollak Policy Analysis and Management Phone: 607-255-2579 Fax: 607-225-0799 pbp3@cornell.edu	http://www.info.cornell.edu http://www.cornell-copc.org/	Working with the university Cooperative Extension office and Public Service Center, which coordinates Cornell's service learning activities, the COPC will address such issues as computer skills training, youth development, family financial management, brownfield identification, neighborhood livability, fair housing, lead-based hazards, access to food and healthcare, and leadership capacity building.
North Carolina	American Social Health Association	SALSA (STDs, Adolescents and Latinos: Sexual Health Awareness)	Centers for Disease Control	James R. Allen, President 919-361-8400	www.ashastd.org	The project's mission and increase the availability of bilingual, culturally appropriate STD prevention and education resources for Latino teens.
	University of North Carolina	Study of the Praise! Project	Pastors and other community members	Dr. Alice Ammerman 919-966-6082	http://www.cmh.pitt.edu/pdf/journalclub/Research_Expectations.pdf	This study sought to examine expectations and satisfaction of pastors and lay leaders regarding a research partnership in a randomized trial guided by community based participatory research methods.
	Down East Partnership for Children	The Child Care Partnership Project	North Carolina Partnership for Children, Smart Start, Surdna and Mary Reynolds Babcock Foundation	Henriette Zalkind, Executive Director 252-985-4300	www.nccic.org/ccpartnerships/profiles/downeast.htm	The program's goal is to ensure that children and their families receive health, education and social services needed to raise healthy children.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
	University of North Carolina at Greensboro Community Outreach Partnership Program	High Point, NC's West Macedonia Neighborhood COPC	City of High Point and its Police Department, Planning and Development Department, Economic Development Corporation, Community Development Department and Housing Authority. Gethsemane Baptist Church, the Boys and Girls Club, the Central Baptist Association, the District Attorney's Office, High Point Family Services, Fairview Elementary School, and Greensboro Public Libraries. UNCG's schools of Business and Economics, Education, and Nursing. Guilford Technical Community College and NCA&T State University Library	Dr. Terri Shelton, Director Center for the Study of Social Issues Phone: 336-334-4423 Fax: 335-334-4435 tlshelto@uncg.edu	http://www.uncg.edu http://www.uncg.edu/csr/	The UNCG COPC is targeting its activities in High Point's West Macedonia neighborhood to help residents address a variety of community issues including the lack of neighborhood cohesiveness, crime, unemployment, low rates of home ownership, and the critical need for youth development.
North Dakota	North Dakota Division of Community Services	Community Development Programs-Strategic Planning Initiatives	Local community leaders, representatives from various agencies	Michael Spletto 701-328-5300	www.state.nd.us/dcs	An initiative to assist communities in creating a vision for their future and identifying and targeting community and economic development activities.
Ohio	City of Delaware (Ohio)	Recreational Trails Project	Delaware Recreational Dept., community members, Ohio Wesleyan Univ. Dept of Geology and Geography	John Krygier 740-368-3622	http://go.owu.edu/~jbkrygie/comgis/comgis_overview.html	Program that worked with community residents to research and plan a comprehensive system of recreational trails in the city of Delaware.
	The Ohio State University Rural Program	Mad River Family Practice	Ohio State University College of Medicine and Public Health	Randall Longenecker, MD, Asst. Dean for Rural Med. Education 937-599-1411	http://www.logan.net/users/mrpf	A rural family medicine residency program in small-town Ohio. They used PAR to develop a community based evaluation of the residency program.
	Center for Health Promotion Research	Evaluation of Teen Pregnancy Prevention in Cuyahoga County	Cuyahoga Board of Health	Elaine A. Borawski, Director 216-368-1617	www.case.edu	This project's mission is to evaluate the effectiveness of the teen pregnancy prevention programs funded by the state of Ohio.

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State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
	Coalition to Access Technology & Networking in Toledo (CATNet)	Technology education program	Adelante, Ability Center of Greater Toledo, Advocates for Basic Legal Equality, Inc, Alpha Community Project, Area Office on Aging, Aurora Academy, Black Data Processors, Association, City of Toledo Department of Neighborhoods, Diocese of Toledo, Fifth Third Bank, Farm Labor Organizing Committee, First Call for Help, Information Technology of Northwest Ohio, Lagrange CDC, League of Women Voters of Toledo-Lucas County, Lutheran Home Services, Mareda, Inc., Mt. Nebo Church, Murchison Center, Neighborhoods in Partnership, Northgate Apartments, North River Development Corporation, Ohio Community Computing Network, Ottawa Community Development Corporation, Seniors Center, Inc, SkyBank, State Farm Insurance, Step Up, Toledo, Toledo-Lucas Library, Toledo Metropolitan Mission, UAW-Chrysler Ohio Training Center, United Way, U of Toledo, Urban University and Neighborhood Network, Vistula Management Company	Anne Robinson, Program Manager 419-530-3528	http://neurbuffweb.ni.utoledo.edu/metronet/catnet/	Program that conducts community participatory research to determine technology needs for individuals in the community who may not have access to technological resources.
	University of Toledo	The community Outreach Partnership Center Program	Various local community partners	Dr. Kenneth Dobson, Economic Director, University of Toledo 419-530-3280	http://www.copc.utoledo.edu/	Goal of program is to empower residents to bring stability to their neighborhoods, provide affordable housing for first- time homebuyers, unite disadvantaged youth, and generate economic development that fosters regional growth.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
	Youngstown State University	The Community Outreach Partnership Center Program	Local residents of the Wick Park Model Neighborhood	Dr. Ronald Chordas 330-742-3113	http://www.cc.yosu.edu/cope	Goal of program is to revitalize the Wick Park Model Neighborhood through an industrial park, job creation, and home ownership opportunities for low and moderate income families.

Exhibit E-1. CBR Projects Listed by State

State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
Oklahoma	Indian Health Service	Indian Health Service Research Program	Cherokee Nation	Paul Weathers, Chair, Cherokee Nation 918-456-0671 x2557	www.ihs.gov	Project to improve the health status and systems of care for the Native-American community.
	Tribal Effort Against Lead (TEAL)	Lead poisoning prevention program	Tribal Nations	Dr. Michelle Kegler 404-712-9957	http://www.niehs.nih.gov/translat/cbpr/projects/kegler.htm	The two-year intervention involved recruiting 40 lay health advisors who attended eight-hour training, and then educate their families, friends, co-workers, neighbors and tribal members on lead poisoning and its prevention.
	Native American Prevention Research Center	Healthy Kids Project	CDC, University of Oklahoma	Dr. June Eichner, co-director 405-271-2330	http://naprc.ouhsc.edu/PROJETS_PROGRAMS_PARTNERSHIPS.asp#HEALTHY_KIDS_PROJECT	The ultimate objective for this project was for it to become a public health screening (i.e., public health practice) supported and performed by the community and school district every year on each student.
Oregon	Oregon Health and Science University	The Oregon Migrant Farmworker Community: An Evolving Model for Participatory Research	Oregon Child Development Coalition, local community leaders	Linda A. McCauley 503-494-4273	http://ehp.niehs.nih.gov/members/2001/suppl-3/449-455mccauley/mccauley-full.html	Research program directed at reducing pesticide exposures among children of migrant workers.
	Oregon Social Learning Center	Early Growth and Development Study	National Institute of Child Health and Development, National Institute of Drug Abuse, local adoption agencies	David Reiss, George Washington University 202-994-2623	http://www.oslc.org/projects.html	The Early Growth and Development Study aims to better understand how heredity and parent-child relationships factor jointly to produce optimal child development.
	Oregon Department of Health Services	SAFE: TEEN Suicide Prevention Program	Oregon Department of Education; American Foundation for Suicide Prevention, Northwest Chapter, Operation Student Safety on the Move (OSSOM)	Charlie Benitez, Student Services- Oregon Department of Education 503-378-3600	http://www.dhs.state.or.us/publichealth/ipe/safeteen.cfm	School-based suicide prevention program which utilizes a self-evaluative tool of the program.

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State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
	University of Oregon	The Community Outreach Partnership Center Program	The Lane County Housing Authority, the St. Vincent de Paul Housing Corporation, the Lane County Public Housing Advisory Committee, the Lane County Family Self-Sufficiency Board, the Metropolitan Affordable Housing Corporation, the university's Community Service Center, and residents and tenant councils from the targeted housing projects.	Dr. David Povey 541-346-3812	http://www.uoregon.edu/~copc/index.htm	Mission of the program is to help residents of 14 local housing projects engage in skill-building and capacity-building programs that will help them achieve self-sufficiency.
Pennsylvania	Community Programs for Clinical Research on AIDS	Philadelphia Fight	Centers for Disease Control and Prevention, National Institutes of Health, U.S.Department of Defense	Jane Shull, Executive Director 215-985-4448 x102	www.fight.org	An initiative on AIDS involving individuals living with HIV/AIDS and clinicians joined together to improve the lives of people living with the disease.
	Early Childhood Partnerships	Early Childhood Initiatives	Heritage Health Foundation, Hosanna House	Stephen J. Bagnato, Director, Early Childhood Partnerships 412-692-6520	www.uclid.org	Early intervention efforts are examined for at risk youth.
	Lesbian Gay Bisexual Transgendered Health Resource Center	The SafeGuards Project	Local community	Dr. Brandon Palermo 215-496-9560	Http://www.safeguards.org/pages/aboutus.asp	The program enhances the health of lesbian, gay, bisexual, and transgender individuals and communities.
	University of Pittsburgh	The Community Outreach Partnership Center Program	The neighborhoods of Central Oakland, South Oakland, West Oakland, Allequippa Terrace/Oak Hill, and Hazelwood in the East End of Pittsburgh.	Mr. Tracy Soska, COPC Co-Director 412-624-3711	http://www.pitt.edu/~copc/index.html	The objective of the program is to address local area's development needs through programs in housing, neighborhood revitalization, economic development, job training, education and health/wellness.
Rhode Island	Center for Research on Education, Diversity and Excellence	School Relationships in Urban Southeast Asian Communities	Brown University	Ronald Tharp, Director 831-459-3500	www.crede.ucsc.edu	The project examines the "at risk" Southeast Asian student community.
	Dana Farber Cancer Institute	Keeping Infants Safe from Smoke (KISS)	Harvard School of Public Health	Dr. Karen Emmons, Principle Investigator 617-632-2188	Http://www2.dfci.harvard.edu/ccbr/projects_events/past/project_kiss.html	Project KISS looked at the effectiveness of a motivational intervention for smokers in lowering their children's exposure to secondhand smoke.
	Rhode Island Department of Health	Rhode Island Tobacco Control Program	RIDH Disease Prevention and Control, CDC	Betty Harvey 401-222-3293	Www.health.ri.gov/disease/tobacco/abouttobacco.htm	Program that identifies disparities related to tobacco use and its effects among different population groups.

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State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
	University of Rhode Island	The Community Outreach Partnership Center Program	Roger William Law School, the Rhode Island School of Design, the Woodlawn Neighborhood Association, the Blackstone Valley Community Action Program, Cape Verdean American Community Development, the Pawtucket Citizens Development Corporation, the Office of the Mayor, and the Pawtucket City departments of Planning and Redevelopment, Recreation, Public Works, and Public Schools.	Dr. Marcia Marker Feld 401-277-5235	http://www.uri.edu	Program goal is to help Woodlawn residents implement community empowerment and revitalization projects.
South Carolina	Medical University of South Carolina	Project SUGAR: Sea Island Genetic African American Family Registry	Sea Island Comprehensive Health Care Center, Franklin C. Fetter Family Health Center	Jyotika Fernandes Principal Investigator 843-792-5158	www.gcrc.musc.edu	The purpose of Project SUGAR is to identify the genes that cause diabetes, obesity and related diseases and complications in African-Americans.
	University of South Carolina Prevention Research Center	Promoting Physical Activity Through Environmental and Policy Supports	Sumter County Active Lifestyles	Steven P. Hooker, PhD 803-777-4253	http://prevention.sph.sc.edu/about/activities.htm	Study concerning the impact of social marketing, policy and environmental support initiatives on increasing physical activity.
	National Breast and Cervical Cancer Early Detection Program	South Carolina Breast and Cervical Cancer Early Detection Program	CDC, community Health Centers, South Carolina Department of Health and Environmental Control	Hellen Deckle 803-545-4103	http://www.cdc.gov/cancer/nbccedp/about.htm	This program helps low-income, uninsured, and underserved women gain access to lifesaving screening programs for early detection of breast and cervical cancers.
South Dakota	South Dakota Department of Health	Coordinated School Health Program	SD Department of Education and Cultural Affairs, local schools and school staff	Linda Ahrendt 605-773-3737	http://www.state.sd.us/doh/SchoolHealth/CoordSchool.htm	This program promotes individual behavior change among students as well as policy changes and social and physical environmental changes in schools.

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State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
Tennessee	East Tennessee State University's College of Nursing	La Coalición Hispano-Americana de la Salud	CDC, local Hispanic community	Dr. Mary Kay Anderson 423-439-4081	http://www.etsu.edu/etsucon/index.htm	The overall purpose of CHAS is to make a lasting positive effect on the health of the Hispanic community.
	University of Tennessee, Chattanooga	The Community Outreach Partnership Center Program	The City of Chattanooga, the Martin Luther King District Redevelopment Task Force, and numerous community organizations.	Michael Hodge 423-785-2342	http://www.utc.edu	The goal of the program is to empower community residents, businesses, and organizations to play a vital role in bringing about change in their community.
Texas	Center for Housing and Urban Development	The Colonias Project	Texas A & M University	Kermit Black, Director 979-862-2370	http://chud.tamu.edu/reg_html/open.htm	A program committed to bettering the health, living environment and nutrition of residents in Texas' colonias.
	St. Luke's Episcopal Health Charities	Healthy Neighborhood Initiatives	The SLEHC Community Health Information System	Dr. Patricia Gail Bray, Executive Director 832-355-3137	http://www.slehc.org/slehc/Home.cfm	A model which is a replicable, neighborhood-based, participatory approach used to advance community health in meaningful and measurable ways.
	National Institute of Environmental Health Sciences, National Institutes of Health	Encuentros Project	The University of Texas at El Paso, Texas Tech University Health Sciences Center at El Paso, the Paso del Norte Center for Border Health Research, Femap Foundation, Organización Popular Independiente, Inc. (OPI), Adults and Youth United Organization (AYUDA), Salud y Desarrollo Comunitario, A.C. (SADEC), Binational Task Force (Junta Directiva).	Dr. Maria Amaya 915-747-5680	http://academics.utep.edu/DesktopDefault.aspx?tabid=6306	The purpose of the project is to evaluate environmental lead exposure among children in the border communities of El Paso, Texas and Cd. Juarez, Mexico using a community-based public health research approach.
	University of Texas at Brownsville and Texas Southmost Collage	The Community Outreach Partnership Center Program	Local residents and community organizations	Armand Mathew, Director 956-983-7659 x956	http://www.utb.edu	The goal of the program is to revitalize the Buena Vida neighborhood in a non-gentrified way.
	Texas A&M School of Rural and Public Health	Prevention Research Center for Rural Community Health Development	Center for Disease Control and Prevention Texas A&M SRPH	Kenneth R. McLeroy, Ph.D., Co-Principal Investigator 979-845-2387	kmcleroy@srph.tamu.edu	Using CBPR in community based interventions to increase access to health and social services, and to disseminate best practices in chronic disease management, in physician practices and the broader community.

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State	Name of Program/ Organization	Name of Project	Partners	Contacts	Web Address	Initiative Summary
Utah	Utah State Office of Education	Improving Character Education Initiatives Through Action Research	Alpine School District, Box Elder School District, Emery School District, Granite School District, Murray School District, North Summit School District, Uintah School District, Washington School District, Weber School District	Jennifer Johns 801-538-7698	www.usoe.k12.ut.us/curr/char_ed	The focus of the action research project was to ascertain general faculty attitudes concerning teaching, preparation, in-service and strengths and weaknesses of schools.
Vermont	National Community Forestry Center, Northern Forest Region	Starksboro, Vermont Community Project	National Community Forestry Center, Starksboro Conservation Commission, local officials and community members	Shanna Ratner 802-524-6141	www.ncfcnfr.net/starksboro.html	Project that developed a set of indicators to evaluate and monitor forest health including social, ecological, cultural, and economic factors.
Virginia	Greater Richmond Chamber of Commerce	Youth Matters/CCFY	Virginia Commonwealth University, local businesses, local leaders	Veronica Templeton, Executive Director 804-783-9352	http://www.youthmattershere.com/index.html	Youth Matters exists to mobilize community resources on behalf of children and youth.
	Virginia Office of Health	Diabetes Control Program	Community members and leaders	Dr. David Suttle, Director 804-864-7651	http://www.vahealth.org/diabetes/newdcp.htm	Program designed to educate communities about diabetes and how to prevent it.
	Danville Community College	The Community Outreach Partnership Center Program	Local residents, churches, community organizations and Community Advisory Councils of Danville, Pittsylvania County, and Halifax County.		http://www.dc.va.us	Program goal is to give residents of target neighborhoods access to education, job training and placement, leadership development, and assistance with neighborhood revitalization and economic development.
	Lynchburg College	The Community Outreach Partnership Center Program	Residents and community organizations of the Tinbridge Hill, College Hill, and White Rock neighborhoods.	Dr. Thomas Seaman 804-544-8327	http://www.lynchburg.edu	Activities of the program focus on community organizing, neighborhood revitalization, economic development, health care, and education of three target neighborhoods of the city of Lynchburg..

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Washington	Neighborhood House	Plain Talk Seattle	National Education Association Health Information Network, Puget Sound Education Services District, SHARP Center	Marsha Vickery 206-461-8379	http://www.aecf.org/initiatives/plaintalk/p2-seattle.htm	Program designed to prevent teen pregnancy in urban communities
	Federal Interagency Working Group on Community-Based Participatory Research	Examining Community-Institutional Partnerships for Prevention Research	National Community Committee, Community-Based Public Health Caucus of the American Public Health Association, Community-Campus Partnerships for Health at the University of Washington School of Public Health and Community Medicine, Community Health Scholars Program, Detroit Community-Academic Urban Research Center, Harlem Health Promotion Center, New York Urban Research Center, Seattle Partners for Healthy Communities, Yale-Griffin Prevention Research Center	Sarena D. Seifer 206-616-4305.	http://depts.washington.edu/ccph/researchprojects.html#ExaminingCommunityPartnerships	The project aims to identify and synthesize what is known about community-academic collaborations in prevention research and develop and evaluate strategies to foster community and institutional capacity for participatory research at national and local levels.
West Virginia	Community Integrated GIS and Appalachia- Southern Africa Research and Development Collaboration	Appalachia- Southern Africa Research and Development Collaborator	Catholic University of Mozambique	Dr. Daniel Weiner, Director, International Programs, West Virginia University 304-293-6955	www.up.ac.za/academic/centre-environmental-studies	West Virginia and Mozambican residents share information in their resource similar environments in this study.
Wisconsin	Bureau of Aging and Long Term Care Resources	Community Links Workforce Projects	Community coalitions	Julie Whitaker 608-266-8778	www.dhfs.state.wi.us/aging/genage/fouryear.htm	Project that stimulated practical approaches for addressing the high vacancy and turnover rates for the state's long term care workers.

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	Medical College of Wisconsin	The Community Outreach Partnership Center Program	Housing Authority of the City of Milwaukee, S.E.T. ministries Inc., Housing Authority Resident Organizations and Councils, the Private Industry Council, the Boys and Girls Club of Greater Milwaukee, the Parklawn YMCA, the Silver Spring Neighborhood Center, and Neighborhood Housing Services.	Ms. Cheryl Maurana 414-456-8291	http://www.mcw.edu	Program activities focus on the areas of community organizing and leadership, violence prevention, health education, economic development, and home safety and ownership in 18 of the city's public housing communities.
Wyoming	Center for Rural Research and Education	Win the Rockies	University of Idaho, Montana State University	Kathy Tatman, Torrington Program Coordinator 307-532-2436	http://uwadmnweb.uwyo.edu/WinTheRockies/	The project seeks to reverse the tide of rising obesity by focusing proactively on prevention at the individual and community level.
	Colorado Injury Control Research Center	Northern Arapaho Tribal Health Department	Indian Health Service, Northern Arapaho Housing Authority, Wind River Police Department	Lorann Stallones, Director 970-491-070	www.psy.psych.colostate.edu/CICRC	Located on the Wind River Reservation, this program addresses an issue of high concern to the community- "wild dog" attacks.

Exhibit E-2. Additional Community Based Research Studies

Acronym	Study Name	Study Reference
AALBH	African Americans Building a Legacy of Health	Sloan DC, Diamant AL, Lewis LB, et al. Improving the nutritional resource environment for healthy living through community based participatory research. <i>J Gen Intern Med</i> 2003; 18(7):568-75.
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. <i>Soc Work</i> 1999; 44(6):549-59.
Oregon Migrants	Oregon Migrant Farm Workers	McCauley LA, Beltran M, Phillips J, et al. The Oregon migrant farm worker community: an evolving model for participatory research. <i>Environ Health Perspect</i> 2001; 109 Suppl 3: 449-55. McCauley LA, Lasarev MR, Higgins G, et al. Work characteristics and pesticide exposures among migrant agricultural families: a community based research approach. <i>Environ Health Perspect</i> 2001; 109(5):533-8.
Chinese Elderly	Chinese American Elderly with Osteoporosis	Lauderdale DS, Kuohung V, Chang SL, et al. Identifying older Chinese immigrants at high risk for osteoporosis. <i>J Gen Intern Med</i> 2003; 18(7): 508-15.
CHEP	Community Health Environment Program	Ledogar RJ, Penchaszadeh , Garden CC, et al. Asthma and Latino cultures: different prevalence reported among groups sharing the same environment. <i>Am J Public Health</i> 2000; 90(6):929-35. Corburn J. Combining community based research and local knowledge to confront asthma and subsistence -fishing hazards in Greenpoint/Williamsburg, Brooklyn, New York. <i>Environ Health Perspect</i> 2002; 110 Suppl 2:241-8.
Controlling Pesticides	Controlling Pesticide Exposure to Children of Farm Workers	Minkler M, Thompson M, Bell J, Rose K. Contributions of community involvement to organizational level empowerment: the federal Healthy Start experience. <i>Health Educ Behav</i> 2001; 28(6): 783-807.
Diabetes In East Harlem	Diabetes In East Harlem	Horowitz CR, Williams L, Bicknell NA. A community centered approach to diabetes in East Harlem, New York. <i>J Gen Intern Med</i> 2003; 18(7):542-8.
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. <i>Health Educ Behav.</i> 2002; 29(1):14-29.
EJS	Environmental Justice Study	Wing S, Wolf S, Intensive livestock operations, health and quality of life among eastern North Carolina residents. <i>Environ Health Perspect</i> 2000; 108(3):233-8. Wing S, Cole D, Grant G. Environmental injustice in North Carolina’s hog industry. <i>Environ Health Perspect</i> 2000;108(3):225-31.
EBFP	Evaluation of the Blended Funding Project	Vander Stoep A, Williams M, Jones R, Green L, Truepin E. Families as full research partners: what’s in it for us?. <i>J Behav Health Serv Res.</i> 1999; 26(3):329-44.
Glades	The Glades Health Survey	Stratford D, Chamblee S, Ellerbrock TV, et al. Integration of a participatory research strategy into a rural health survey. <i>J Gen Intern Med</i> 2003; 18(7): 586-8.
Harlem Birth Right	The Harlem Birth Right Project	Mullins L, Wali A, McLean D, et al. Qualitative methodologies and community participation in examining reproductive experiences: the Harlem Birth Right Project. <i>Matern Child Health J</i> 2001; 5(2):85-93.

Exhibit E-2. Additional Community Based Research Studies

Acronym	Study Name	Study Reference
HNP	Healthy Neighborhoods Project	El-Askari G, Freestaone J, Irizarry C, et al. The healthy Neighborhoods Project: a local health department's role in catalyzing community development. <i>Health Educ Behav</i> 1998; 25(2):146-59. Minkler M. Using Participatory Action research to build Healthy Communities. <i>Public Health Rep</i> 2000; 115(2-3):191-7.
HERE	HERE	Lee PT, Krause N. The impact of worker health study on working conditions. <i>J Public Health Policy</i> 2002; 23(3): 268-85.
Housing Options	Housing Options	Stajduhar KI, Lindsey E. Home away from home: essential elements in developing housing options for people living with HIV/AIDS. <i>AIDS Patient Care Stds.</i> 1999; 13(8):481-91.
Madison County	Madison County	Paul T, Landis S, Trevor J. Enhancing Participatory Research with the Community Oriented Primary Care Model: A Case Study in Community Mobilization. <i>Am Sociol</i> 1992: 56-70.
Native Hawaiian	The Native Hawaiian Smokers Survey	Tsark JA. A participatory research approach to address data needs in tobacco use among Native Hawaiians. <i>Asian Am Pacific Islander J Health.</i> 2001-2002; 9(1): 40-8.
PAR CHP	Participatory Action Research for Community Health	Rains JW, Ray DW. Participatory action research for community health promotion. <i>Public Health Nurs</i> 1995; 12(4):256-61.
PAR Hmong	Participatory Action Research with Hmong Women	Yoshihama M, Carr ES. Community Participation Reconsidered: Feminist Participatory Action Research With Hmong Women. <i>J Comm Pract</i> 2002; 10(4):85-103.
Perspectives in Latina Women	Perspectives of Pregnant and Postpartum Latina Women on Diabetes, Physical Activity and Health	Keiffer EC, Willis SK, Arellano N, et al. Perspectives of pregnant and postpartum Latina women on diabetes, physical activity, and health. <i>Health Educ Behav</i> 2002: 29(5):542-56.
Positively Fit	Positively Fit	Hiebert W, Swan D. Positively Fit: A Case Study in Community Development and the Role of Participatory Action Research. <i>Comm Devel J</i> 1999; 34(4): Oct, 356-64.
Poultry Slaughterhouse	Poultry Slaughterhouse Study	Mergler D. Worker Participation in occupational Health Research: Theory and Practice. <i>Intl J health Serv</i> 1987; 17(1):151-67.
South Asian	South Asian Women	Choudhry UK, Janu S, Mahal J, Singh R, Sohi Pabla H, Mutta B. Health promotion and participatory action research with South Asian women. <i>J Nurs Scholarship</i> 2002; 34(1):75-81.
TAS	Together for Agriculture Safety Project	Flocks J, Clarke L, Albrecht S, et al. Implementing a community based social marketing project to improve agricultural worker health. <i>Environ Health Perspect</i> 2001;109 Suppl 3:461-8.
Welcome Home	Welcome Home Ministries	Parsons ML, Warne-Robbins C. Formerly incarcerated women create healthy lives through participatory action research. <i>Holistic Nurs Pract</i> 2002; 16(2): 40-9.

Exhibit E-2. Additional Community Based Research Studies

Acronym	Study Name	Study Reference
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. Kinney PL, Aggarwal M, Northridge ME, et al. Airborne concentrations of PM(2.5) and diesel exhaust particles on Harlem side walks: A Community Based Pilot Study. Environ Health Perspect 2000; 108(3):213-8.