

# Chapter 24

## COMMUNITY-BASED PARTICIPATORY RESEARCH: AN OVERVIEW FOR APPLICATION IN DEPARTMENT OF DEFENSE/VETERANS AFFAIRS RESEARCH

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### INTRODUCTION

#### **NINE PRINCIPLES OF COMMUNITY-BASED PARTICIPATORY RESEARCH**

**Principle 1: Recognize That the Community Is a Unit of Identity**

**Principle 2: Identify and Build on Strengths and Resources Within the Community**

**Principle 3: Facilitate a Collaborative, Equitable Partnership Throughout All Phases of Research**

**Principle 4: Foster Co-learning and Capacity Building Among All Partners**

**Principle 5: Integrate and Achieve Balance Between Knowledge Generation and Intervention for the Mutual Benefit of All Partners**

**Principle 6: Realize That Research Should Be Driven by the Community Addressing Locally Relevant Public Health Problems**

**Principle 7: Develop a System to Encourage a Cyclical, Iterative Process**

**Principle 8: Make Sure That Communication of Research Findings Is Disseminated to All Partners and That Partners Are Involved in the Wider Dissemination of Results**

**Principle 9: Understand That Community-Based Participatory Research Involves a Long-Term Process and a Commitment to Sustainability**

### SUMMARY

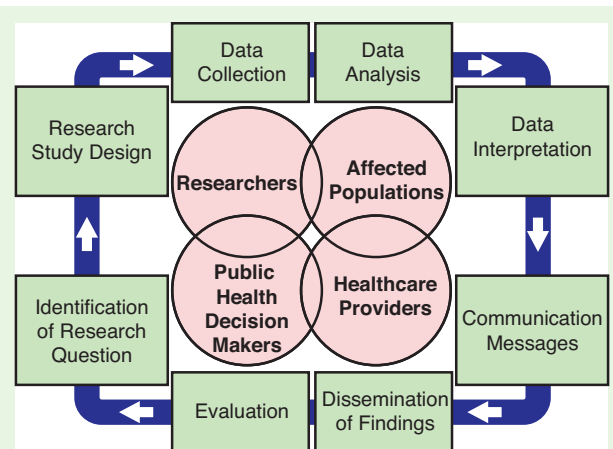
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## INTRODUCTION

Community-based participatory research (CBPR) is an approach to research that promotes active involvement with community partners or stakeholders. It begins at the generation of a research question and continues through dissemination of results, policy decisions, and/or interventions. CBPR fosters collaboration among research scientists and people affected by the issue under investigation (eg, community members, active military personnel, veterans, and patients with a particular disease). Decision makers (public health policymakers and organizational leaders) who can apply research findings for the benefit of all research partners typically join these partnerships. Proponents of participatory research have reported that these partnerships have yielded great benefits to the research study, including

- increasing the capacity for data collection, analysis, and interpretation;
- reducing the “iatrogenic” effects of research;
- enhancing the relevancy of research questions; and
- maximizing the return of research to improve policy and practice.<sup>1-6</sup>

Over the past few decades, participatory research has gained momentum across academic institutions, community-based organizations, and federal agencies. The National Institute of Environmental Health Sciences (NIEHS) has taken a lead within the National Institutes of Health in applying and funding active community/stakeholder participation in research.<sup>7,8</sup> NIEHS recently initiated the Partnerships for Environmental Public Health umbrella program.<sup>9</sup> The goal of this program is to engage communities in all stages of research, outreach, and educational activities to prevent, reduce, or eliminate environmental exposures that may lead to adverse health outcomes, with particular emphasis on populations at highest risk. Within the NIEHS portfolio of research funding announcements, community participation in research is either strongly encouraged or is a required element of the research proposal. For example, in 2012, NIEHS launched a funding opportunity titled *Research to Action: Assessing and Addressing Community Exposures to Environmental Contaminants*. Engagement of those affected by exposures is a requirement of the funding



**Figure 24-1.** Overview of the process of community-based participatory research. Key steps of the cyclical research process are outlined and demonstrate that the research study team includes researchers, affected populations, public health decision makers, and healthcare providers. Their input is needed throughout the research process.

announcement. As illustrated in Figure 24-1, participatory research calls on the skill of individuals with diverse expertise, including members of the affected population, public health decision makers, healthcare providers, and scientific researchers. These individuals are part of the collaborative research team that is involved in the research process from conception of the research question, study design, conduct, analysis, interpretation, and conclusions to communication of results.

CBPR stemmed from the understanding that communities of disadvantage have higher morbidity and mortality as a result of socioeconomic status. Participatory research was initially conceived to improve the health of disadvantaged populations, as defined by socioeconomic status, race, or location. The guiding principles of CBPR can be useful when developing research involving active military and veterans. Therefore, the principles of CBPR are explained herein with relevance to active military and veterans research.

## NINE PRINCIPLES OF COMMUNITY-BASED PARTICIPATORY RESEARCH

In 1988, Dr Barbara Israel and colleagues<sup>1</sup> identified nine guiding principles of CBPR to help guide the CBPR process. These principles are outlined in Exhibit 24-1 and are general guidelines that can be adapted to fit a particular research project. Although they are presented in this chapter

as distinct items, their collective integration is essential to the conduct of participatory research. Because each research study is unique and requires multidisciplinary expertise, each partnership is also unique and requires a tailored approach. Even though all nine principles of participatory research are

described in this chapter, it is anticipated that a subset of these principles will be modified and selected for effective implementation of participatory research within Department of Defense (DoD) and Department of Veterans Affairs (VA) funded research.

### **Principle 1: Recognize That the Community Is a Unit of Identity**

The concept of community as a separate entity is critical to CBPR.<sup>1</sup> A community extends well beyond a neighborhood and is defined based on the perception of the community. For example, a community may be defined as a group of individuals who have a shared set of values and norms, common symbol systems, common environmental exposures, common disease, emotional connection to each other, and commitment to shared goals. With respect to the military, a community may represent a group with a particular exposure, disease, or service during a particular timeframe.

To conduct the research effectively, individuals and organizations outside of the identified community may need to be included in the research partnership. These may include community-based organizations, representatives from health service organizations, healthcare professionals, academia, or others identified by the community who can provide useful resources and skill sets to the research agenda.

### **Principle 2: Identify and Build on Strengths and Resources Within the Community**

Each community has unique strengths and resources that can be useful to the research study. Recognition and implementation of this principle enlighten not only the scientific researcher, but also the community itself to these potential resources and strengths. Community members have expertise and vast social experiences that may not be found in the scientific researcher. CBPR recognizes that the expertise of the community members is equally as beneficial to the research study as the knowledge of the research scientist. Participatory research recognizes the value in each partner's expertise and their view of the problem.

Community members or affected individuals should be regarded as experts. Affected individuals understand the community better than the scientist. They can provide expertise in sources of exposure, timing of exposure, and potential confounders. For example, in a study of air pollution, affected individuals would know when exposures would most likely occur, who might be most exposed, and characteristics about the affected population that may increase exposure. In addition, members of the affected community can also provide expertise in how results are communicated back to the community and through what mechanisms. Inclusion of this expertise enhances the relevance of the research study in its potential to decrease exposure and improve the health of the population. A

#### **EXHIBIT 24-1**

#### **NINE GUIDING PRINCIPLES OF COMMUNITY-BASED PARTICIPATORY RESEARCH**

##### **Principle 1**

Recognize that the community is a unit of identity

##### **Principle 2**

Identify and build on strengths and resources within the community

##### **Principle 3**

Facilitate a collaborative, equitable partnership throughout all phases of research

##### **Principle 4**

Foster co-learning and capacity building among all partners

##### **Principle 5**

Integrate and achieve balance between knowledge generation and intervention for the mutual benefit of all partners

##### **Principle 6**

Realize that research should be driven by the community addressing locally relevant public health problems

##### **Principle 7**

Develop a system to encourage a cyclical, iterative process

##### **Principle 8**

Make sure that communication of research findings is disseminated to all partners and that partners are involved in the wider dissemination of results

##### **Principle 9**

Understand that community-based participatory research involves a long-term process and a commitment to sustainability

literature review of CBPR intervention studies by the Agency for Healthcare Research and Quality found that community involvement enhanced the element of intervention quality, such as enhanced recruitment efforts, improved research methods and dissemination, and improved descriptive measures.<sup>10</sup>

### **Principle 3: Facilitate a Collaborative, Equitable Partnership Throughout All Phases of Research**

It is well recognized that the successful conduct of research requires a multidisciplinary approach, in which experts are invited to participate in the research to benefit scientific discovery with the ultimate goal of improving public health. Once community partners are regarded as experts, then their role in the conduct of the research study becomes equitable. This principle ensures that expertise from the affected community is included in all phases of the research study. Community partners become equally important in the decision-making processes that frame the research study as the scientific experts.

Scientists can facilitate this equality by including members of the affected community on the research study team. During research study meetings, community partners should be encouraged to contribute to each phase of the research study, including identification of the problem or issue that needs to be addressed through research; how data are collected; interpretation of results; and communication of research findings to study participants and others. The advice of partners should be sought as questionnaires are developed, biological and environmental data collection are being planned, potential confounds are being discussed, etc. Once the study is launched, the community partner still remains integral to the research study team. The partner can provide insight into effective study recruitment mechanisms and assist in troubleshooting data collection issues. Also, the expertise of the partner is critical to the interpretation of data analyses and identification of the public at large.

### **Principle 4: Foster Co-learning and Capacity Building Among All Partners**

Co-learning occurs as scientists and community partners begin to share their experiences in the context of the research study. For example, if a research scientist investigated the health impacts associated with carpentry, the scientist would highly benefit from learning about the lifestyle and work experiences of a carpenter. These may include work hours, ergonomic issues, or other hazards on the job not previously considered by the researcher. In turn, the carpenter would gain knowledge on the conduct of research and, ultimately, how to improve working conditions and practices to improve

occupational health and safety. This co-learning occurs when representatives of the study population become integral members of the research team.

To foster co-learning in the research collaboration, the capacity of each—the scientist and the carpenter—needs to be enhanced. To build capacity of the scientist in this example, he/she may need to visit the carpentry site to witness the potential exposures and customary practices of carpenters and learn the names of trade tools. The carpenter will need to understand the purpose of the research, what is involved in conducting a research study, and how funding is obtained to support the research. Community partners should be part of the decision-making process for selecting what capacity they need built. For example, in a CBPR research study in Marietta, OH, where residents were concerned about air quality and health, the community partners asked for workshops on air particles and health to further understand air sampling and the potential health impacts of various-sized particles.<sup>11</sup>

### **Principle 5: Integrate and Achieve Balance Between Knowledge Generation and Intervention for the Mutual Benefit of All Partners**

Within CBPR, it is anticipated that the research conducted is beneficial for all partners. Research scientists add to the scientific literature and expand their specific fields, whereas community partners have an improved understanding of their particular concern. CBPR highlights the importance of applying the knowledge gained from research into an intervention that will help solve the community's initial concerns. This integration or application of the science into appropriate interventions provides a win-win situation in which scientists walk away with a better-conducted study because of the contribution of the community partners, whereas community members receive a solution to their problem.

Community organization has been identified as an essential element for successful implementation of community-based cardiovascular disease prevention programs.<sup>12</sup> When key community leaders and community organizations are mobilized, health promotion becomes a community theme, and time and resources are more readily available for prevention activities.

### **Principle 6: Realize That Research Should Be Driven by the Community Addressing Locally Relevant Public Health Problems**

The conduct of science is the systematic investigation of a question. In CBPR, the scientific research question is identified by the community and that question has arisen

from their concern or problems with a particular exposure or health outcome. In participatory research, the community's struggle with understanding the issue or problem is co-shared with scientists and jointly investigated. Addressing a community-driven issue is integral to CBPR. It ensures that the research is community relevant and will potentially result in mitigation of the exposure or other intervention that will negate the problem.

### **Principle 7: Develop a System to Encourage a Cyclical, Iterative Process**

Implementing CBPR is not a one-time meeting of scientists and community partners. CBPR requires multiple meetings throughout the research study to ensure that the needs of all partners are being met. This cyclical, iterative process ensures that all research team members have an equal opportunity to contribute during each phase of the research study from problem definition to dissemination of results and action taken, if appropriate. This also ensures that the action taken as a result of the research is acceptable and appropriate for all partners.

### **Principle 8: Make Sure That Communication of Research Findings Is Disseminated to All Partners and That Partners Are Involved in the Wider Dissemination of Results**

Communication of study results is an essential outcome of the community–scientist collaborative research process. All study partners should have access to study results, and great care should be taken to develop communication mechanisms that are appropriate, accessible, and respectful of all partners. This principle also extends to the involvement of community research partners as co-authors of publications, scientific reports, abstracts, and co-presenters at scientific meetings and conferences.

Community partners provide expertise in guiding the

development of effective communication messages and strategies for the target population, including study participants and the public at large. As members of the affected community, they can best identify the messages and determine which strategies to deliver those messages would be the most effective.

### **Principle 9: Understand That Community-Based Participatory Research Involves a Long-Term Process and a Commitment to Sustainability**

Development of community-based partnerships necessitates the building of mutual trust and respect. CBPR is a long-term process and requires a commitment to the partnership from all members. When CBPR is implemented, the community partners have identified the research question, provided their expertise for the enhancement of the project, and assisted in the conduct of research and study results dissemination; they are truly vested in the research. Arguably, they have a greater investment in the research than the scientist because the issue under investigation is one that directly affects the health and safety, livelihood, and well-being of their families. Thus, once the research study is complete, it is critical that the partnership does not end. Scientists need to retain the commitment to the partnership even when funding is not available. Maintenance of the partnership requires sustained communication and capacity building for the partners.

A research study operating under CBPR guidelines will not end the partnership once data are collected. As described in Principle 5, the research scientist would also work with the affected community to use the information gained from the study to improve the working or living conditions of research partners. This could be in the form of participating in advocacy for policy change, publishing research findings in peer-reviewed journals to demonstrate credibility of the work, and sharing these results in the form of publications with public health decision-makers engaged in policy decisions relevant to the issue. This step is critical because it sustains the community's trust in the research scientists and the research process.

## **SUMMARY**

Participatory research is a partnership approach that provides an equitable foothold in the research process for all involved. The participatory research approach recognizes that every member of the research team, including representatives from the community, have unique strengths and expertise. Although nine participatory research principles were described, it is not anticipated that the DoD/VA will endorse all of them. For example, the NIEHS endorses only six of the nine guiding principles of CBPR:

1. promotes active collaboration and participation at every stage of research,
2. fosters co-learning,
3. ensures that projects are community-driven,
4. ensures that research and intervention strategies are culturally appropriate,
5. defines community as a unit of identity, and
6. disseminates results in useful terms.<sup>6</sup>

Because the nature of research conducted and funded by the DoD/VA and NIEHS have strong similarities, it is recommended that at least the six principles endorsed by NIEHS be considered for implementation in active military and veteran research. The selection process should be a participatory process involving active military and veterans, as well as research scientists within the DoD/VA. It is also recommended that at least one member of the selection committee have expertise in CBPR. Strong consideration should be made to determine which of the guiding CBPR principles

would best serve their research mission. There is little doubt that application of these principles will significantly

- increase research study relevance;
- enhance data collection, interpretation, and analysis;
- improve the capacity of all research partners;
- improve communication of research findings; and
- improve the health and well-being of active military and veterans as the findings are implemented into effective policy and practice.

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