



COMMUNITY-BASED PARTICIPATORY RESEARCH

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COMMUNITY-BASED
PARTICIPATORY
RESEARCH



This book is dedicated to my husband Eric Menninger,
and my sons Elias and Nate

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Prospectus

Community-Based Participatory Research

❖ MISSION OF THE TEXT

Research-based health care innovations make their way slowly, if at all, into community practice. It is the goal of community-based participatory research (CBPR) to create an effective translational process that will improve population health and increase connections with members of underserved communities.

Historically, research involving communities has not included community partners in a participatory manner. As a result, members of underserved communities often feel that research has been conducted upon them rather than with them. Rather than seeing potential community benefits from health care research in their communities, community members may feel exploited by researchers. The worst-case scenarios such as the Tuskegee experiment have left many communities, particularly those of color, feeling distrustful and reluctant to participate. Consequently, research that has the potential to improve health may not result in action or sustainable change at the community level.

The CBPR approach seeks to improve the relevancy and acceptability of research and break down translational barriers. Members of underserved communities increasingly demand a new approach in which they are equal participants in the development and conduct of the research and in which the research has direct benefits for the people involved. CBPR aims to achieve these goals. In addition to health care, the CBPR approach is being used in education, psychology, and social work. In these various disciplines, community members are partnering with investigators who possess a variety of skills that will help improve the health and/or well-being of community members.

CBPR has been used successfully to help communities confront challenges ranging from youth suicide and violence to growing obesity trends.

This book was written to provide a succinct and easy-to-read practical guide to community-based participatory research. The book describes how an individual researcher might understand and then actually conduct CBPR research. It is thus a how-to book that uses case examples throughout. Both the benefits and challenges of the approach will be discussed, as well as the basic steps involved in CBPR projects. The book will also explore the unique ethical questions that arise in CBPR projects.

To date, comprehensive texts on CBPR are available but do not provide a practical guide to CBPR. Whereas other key texts cover the CBPR areas in depth, they do not offer a how-to approach to CBPR. With this book, students and teachers will have a short, easily accessible guide to CBPR that helps them as they consider and conduct CBPR in the field. It includes exercises at the end of each chapter with important take-home points. Additionally, this book will be available across a wide range of disciplines. The book will be seen primarily as a supplement for classes on research methods and substantive courses ranging from sociology to public health; it uses examples throughout emanating from the United States rather than Europe or Australia; it can be a valuable resource for both practitioners and community members.

❖ THE MARKET/COURSES FOR THE BOOK

The market for this book is diverse and includes students studying research methods in both the social sciences and medicine. The book could be used at either the undergraduate or graduate level in social work, sociology, psychology, education, public health, or medicine.

It might be helpful in the following types of courses:

- Action research
- CBPR, participatory research
- Research methods
- Evaluation
- Community organizing
- Clinical translational science

Professional organizations and journals that might have interest: American Public Health Association, Society of General Internal

Medicine, The National Institutes of Health Clinical Translational Science Awards, *American Journal of Public Health*, *Journal of General Internal Medicine*, *Journal of Preventive Medicine*, *Progress in Community Health Partnerships: Research, Education and Action*, *Clinical and Translational Science*, Community Campus Partnerships for Health, and community groups and organizations.

❖ THE MAJOR FEATURES OF THE BOOK AND BENEFITS OF THESE FEATURES

This book features short chapters that are clearly written in a “friendly,” accessible manner that will appeal to beginners as well as community members while remaining sophisticated enough for researchers already involved in CBPR. Cases are interwoven throughout the chapters that help the reader apply the concepts that are outlined. In addition, basic tables are available to help visual learners and to summarize major concepts. Each chapter concludes with a set of activities for the classroom and, in some cases, questions for discussion. The chapter on the community perspective offers a perspective and practical concepts often overlooked in texts on the subject. The chapter on the steps in CBPR allows readers to get an understanding of steps in CBPR that can be practically applied in their own work. The book is also short enough to be seen as a supplement to other methods textbooks.

❖ THE SPECIAL PEDAGOGICAL AIDS AND HIGH-INTEREST FEATURES

Each chapter concludes with a set of questions and/or activities that are available for implementation in the classroom. CBPR is a participatory approach, and students need to experience and practice elements of the approach. When possible, it is advisable to attach field work to a CBPR course. Should this not be practical, exercises and activities that allow students to apply their knowledge in the classroom will be helpful.

❖ ACKNOWLEDGMENTS

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Brief Contents

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Principles of Community-Based Participatory Research



“Community-based participatory research is a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change.”¹



In this chapter, I will provide an overview of community-based participatory research (CBPR) and accomplish the following objectives:

- Review the principles and foundations of CBPR
- Discuss the rationale for involvement in CBPR and when to use it (why bother?)

- Introduce cases in which CBPR was used to investigate
 - Policy issues
 - Urgent health crises
 - Health disparities
- Compare CBPR with traditional research
- Describe the strengths and weaknesses of a CBPR approach

❖ OVERVIEW OF COMMUNITY-BASED PARTICIPATORY RESEARCH

As is so often the case in community health practice, a problem is met head on with a solution. Unfortunately, while the solution represents a response to an urgent identified need, it often lacks an evidence base. We recognize that research-based innovations make their way slowly, if at all, into community practice.^{2,3} This has been documented extensively in the literature with regard to health in particular and speaks to the breakdown between academic and community-based practitioners. How can we speed the uptake of evidence into community practice? How can we identify the appropriate community-relevant research questions? How can we break down the barriers between researchers and community partners? How can communities translate their own practice-based evidence for consumption by the research community? There is a great deal of current interest in strategies to improve the rapidity of the translational research process.⁴ Engaging the community may be one way to bridge the gap between science and practice.

Community-engaged research (CeNR) exists on a continuum ranging from research in the community setting to research that fully engages community partners. CBPR represents one end of this CeNR spectrum (Figure 1.1). The CBPR approach encourages engagement and full participation of community partners in every aspect of the research process from question identification to analysis and dissemination.

The goal of CBPR is to create an effective translational process that will increase bidirectional connections between academics and the communities that they study. This approach is not limited to specific disciplines but can be utilized whenever conducting community research. CBPR hinges on the relationship between the researcher and the community under study. The equitable aspects of the partnership and the participatory nature of the work differentiates CBPR from other traditional research approaches. In addition, in CBPR, there is a close linkage between the academic pursuit of generalizable knowledge and the use of that knowledge for action at the local level. Thus the practice of

Figure 1.1 Community-Engaged Research Continuum

Source: Virginia Commonwealth University Center for Clinical and Translational Research 2008 (Looking at CBPR Through the Lens of the IRB. Cornelia Ramsey, PhD, MSPH Community Research Liaison, Center for Clinical and Translational Research, Division of Community Engagement, Department of Epidemiology & Community Health) <http://www.research.vcu.edu/irb/Looking-at-CBPR-Through-the-Lens-of-the-IRB.ppt>

CBPR takes a somewhat different track than that of traditional research. Throughout this chapter, I will focus on the rationale for CBPR, the principles, and the strengths and weaknesses of the approach in order to prepare the investigator to engage in CBPR projects.

Historically, research involving communities has not always included community partners in a participatory manner. Rather, research may be done in communities or on community residents, using the community as a laboratory. As a result, members of underserved communities often have negative perceptions of research and may feel exploited by investigators who conduct research, depart, and leave nothing behind. The worst-case scenarios such as the Tuskegee experiment have left many community members, particularly those of color, feeling distrustful and reluctant to participate in research.⁵ Thus, research that may improve health and other outcomes may not include populations at highest risk or result in action or sustainable change at the community level.

In order to improve the relevancy and acceptability of research to communities and break down translational barriers, community members are increasingly demanding equality in the development and conduct of research. In addition, they are interested in shared ownership of the resulting data and in the application of results to action in practice or policy. In short, they want to have their voices heard and to participate in shaping the topics for study, identifying the emergent questions, and conducting investigations into the issues that are meaningful to their

communities. They want to be part of the research team and see that the results are utilized to remedy problems at the community level.

Changing the research paradigm to include community members in a participatory manner requires a new approach that includes the formation of equitable partnerships between academia and community members in which there is mutual respect and both parties contribute and benefit. Thus, the goal of the CBPR approach is to produce research that is relevant to the life circumstances of communities and the people who reside within them.⁶ When embraced by community partners as a shared endeavor, CBPR has the potential to catalyze actionable health improvement in real time.

❖ THE FOUNDATIONS OF CBPR

CBPR is only recently finding its way into the biomedical literature. However, it has been previously used in a variety of disciplines ranging from anthropology to education and psychology. Sometimes called “action research,” “participatory research,” “participatory action research,”⁷ or even “street science,”⁸ it has been used to examine environmental health issues, educational strategies, and international health issues.⁹ These “participatory research” approaches share a core philosophy of inclusivity and of engaging the beneficiaries of research in the research process itself.¹⁰ Similarly, CBPR is built on a foundation of social justice and empowerment, with its roots in feminist theory and community organizing. Feminist theory focuses on the historical and cultural oppression of women and drives toward gender equality and empowerment.¹¹ Community organizing purports that individuals together can make a difference in their own communities through group action.^{12, 13} Both of these theories recognize that empowerment of the oppressed can result in community action for social change.

Two distinct traditions—that of Kurt Lewin, who coined the term *action research*, and that of Paulo Freire, who developed “emancipator research”—stand out as having influenced CBPR. Kurt Lewin in the 1940s was one of the first to use the term *action research*. Lewin sought to solve practical problems using a research cycle that involved planning, action, and investigation of the results of action.^{7, 14} This iterative process paired the researcher with community members as partners in the investigative process. In 1970, Paulo Freire, the Brazilian educator, changed the power dynamics in research by depicting the researcher as facilitator and catalyst rather than director in his book, *Pedagogy of the Oppressed*.¹⁵ As Freire noted, knowledge is connected to power—but whose power?