

PREFACE

PREFACE: COMMUNITY-PARTNERED PARTICIPATORY RESEARCH: HOW WE CAN WORK TOGETHER TO IMPROVE COMMUNITY HEALTH

Loretta Jones, MA

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Dramatic new medical advances offer opportunities to prevent or reduce the impact of many chronic health problems. In many cases, these clinical advances have resulted from progress in research.

But advances in research and clinical knowledge often do not reach the streets – particularly when those streets are located in poor, minority or under-served neighborhoods. In too many communities across the nation, the promise of new research findings has not translated into better medical care strategies or improved health outcomes.

The gap between the promise of science and the realities of community practice has inspired many changes in the purposes and methods of research. For example, a recent emphasis on practical trials, those designed to evaluate how treatments work in real practice, is producing a new generation of medical research designed to be more relevant to medical practice. However, even when research findings are practical, they may not result in better community health, especially if community stakeholders feel that the research is irrelevant to their needs, insensitive to their culture, inconsistent with their resources, or conducted by institutions with histories of poor community relations.

This supplement of *Ethnicity & Disease* presents a guidebook, which is based on the premise that the science-community practice gap can be closed by engaging diverse community stakeholders and academics together in a two-way learning process from beginning to end, in a process we call Community-Partnered Participatory Research (CPPR). We define community stakeholders very broadly: everyone who is interested in, or affected by, a particular issue. We focus on community engagement as the key collaboration concept for partnered research, because community involvement is not enough. Community members may be involved in a project, (eg, as research participants or advisors) without being truly engaged in the project. We suggest that in order for research to: 1) focus effectively on community needs, 2) enable the community to use research products and findings, and 3) have

enough traction to translate findings into action, community stakeholders must be true research partners, with equal decision-making power. A CPPR project includes community and academic partners in all phases of research and decision-making, shares leadership and resources equitably, highlights the critical importance of evidence while simultaneously valuing the relevance of experience, and emphasizes two-way capacity development.

Public health practitioners and public health academics have long worked closely with community stakeholders. But this approach is still quite new to clinical and medical research. Our central goal in writing this guidebook is to facilitate community engagement in such research.

The authors of this guidebook include both community and academic partners, whose experiences and lessons are summarized based on what we have learned from working together on a variety of health-related projects during a 10-year period. Our projects have been funded by, and developed in collaboration with, the Centers for Disease Control and Prevention, the Robert Wood Johnson Foundation Clinical Scholars Program, the National Institutes of Health, the National Institute of Mental Health, and the National Institute of Child Health and Human Development.

We found that the challenges of building sustainable community-academic partnerships are many. As we began working together to share what we had learned, we realized that the precedents for rigorous, partnered research across diverse community stakeholders and academic medical scholars are relatively few. The purpose of this guidebook is to share what we have learned with others interested in improving community health.

We expect that our readers will be community members, academics, and clinicians who are embarking together on a community-academic research partnership. We acknowledge that what we have learned is only a small part of what we need to learn. *We hope that as you work on your own community-academic research partnerships, you will share what you learn with us.*

Appendix 1 contains return pages that we ask you to fill out and return to us. Your input will shape the next edition of this guidebook and, we hope, help others as they work to improve both academic research and community life.

Address reprint requests and correspondence to Loretta Jones, MA; Healthy African American Families II (HAAF); 3756 Santa Rosalia Drive, Suite 320, Los Angeles, CA 90008; 323.292.2002; 323.292.6121 (fax); LJonesHAAF@aol.com

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We hope that this guidebook will help community and academic partners to develop a vision, work together to accomplish goals, and celebrate achievements.

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