

Handbook of Community-based Participatory Research

edited by

Steven S. Coughlin

Selina A. Smith

Maria E. Fernandez

OXFORD

Handbook of Community-Based Participatory Research

EDITED BY STEVEN S. COUGHLIN

SELINA A. SMITH

and

MARIA E. FERNANDEZ

OXFORD
UNIVERSITY PRESS

Oxford University Press is a department of the University of Oxford. It furthers the University's objective of excellence in research, scholarship, and education by publishing worldwide. Oxford is a registered trade mark of Oxford University Press in the UK and certain other countries.

Published in the United States of America by Oxford University Press
198 Madison Avenue, New York, NY 10016, United States of America.

© Oxford University Press 2017

All rights reserved. No part of this publication may be reproduced, stored in a retrieval system, or transmitted, in any form or by any means, without the prior permission in writing of Oxford University Press, or as expressly permitted by law, by license, or under terms agreed with the appropriate reproduction rights organization. Inquiries concerning reproduction outside the scope of the above should be sent to the Rights Department, Oxford University Press, at the address above.

You must not circulate this work in any other form
and you must impose this same condition on any acquirer.

Library of Congress Cataloging-in-Publication Data

Names: Coughlin, Steven S. (Steven Scott), 1957– editor. | Smith, Selina A., editor. | Fernandez, Maria E. (Maria Eulalia), editor.

Title: Handbook of community-based participatory research / edited by Steven S. Coughlin, Selina A. Smith, Maria E. Fernandez.

Other titles: Community-based participatory research

Description: Oxford ; New York : Oxford University Press, [2016] | Includes bibliographical references and index. | Description based on print version record and CIP data provided by publisher; resource not viewed.

Identifiers: LCCN 2016031904 (print) | LCCN 2016030512 (ebook) |

ISBN 9780190652241 (e-book) | ISBN 9780190652258 (e-book) |

ISBN 9780190652234 (paperback : alk. paper)

Subjects: | MESH: Community-Based Participatory Research

Classification: LCC R850 (print) | LCC R850 (ebook) | NLM W 84.3 |

DDC 610.72/4—dc23

LC record available at <https://lcn.loc.gov/2016031904>

This material is not intended to be, and should not be considered, a substitute for medical or other professional advice. Treatment for the conditions described in this material is highly dependent on the individual circumstances. And, while this material is designed to offer accurate information with respect to the subject matter covered and to be current as of the time it was written, research and knowledge about medical and health issues is constantly evolving, and dose schedules for medications are being revised continually, with new side effects recognized and accounted for regularly. Readers must therefore always check the product information and clinical procedures with the most up-to-date published product information and data sheets provided by the manufacturers and the most recent codes of conduct and safety regulation. The publisher and the authors make no representations or warranties to readers, express or implied, as to the accuracy or completeness of this material. Without limiting the foregoing, the publisher and the authors make no representations or warranties as to the accuracy or efficacy of the drug dosages mentioned in the material. The authors and the publisher do not accept, and expressly disclaim, any responsibility for any liability, loss, or risk that may be claimed or incurred as a consequence of the use and/or application of any of the contents of this material.

9 8 7 6 5 4 3 2 1

Printed by Webcom Inc., Canada

Preface

As a collaborative approach to research, community-based participatory research (CBPR) equitably includes all partners in the research process and often involves partnerships between academic and community organizations with the goal of increasing the value of the research product for all partners. In the past, social scientists and researchers who focused on disease prevention tended to conduct studies of social phenomena and community problems with an “outsider’s approach” which distanced the research from the participants’ daily lives. This approach was questioned by theorists such as Kurt Lewin and Paulo Freire, who proposed more participatory and inclusive methods. As detailed in chapter 1 by Steven Coughlin, Selina Smith, and Maria Fernandez, and in several other chapters in this volume, current perspectives seek to address the complexity of the human experience and the differential power that sometimes exists between academic researchers and research participants.

Community-based participatory research is linked to other social justice-informed methodologies to research (e.g., action research, participatory action research, and participatory learning and action) that attempt to empower communities to address the root causes of inequality and identify their own problems and appropriate solutions. Community-based participatory research strives to acknowledge and implement the participants’ needs, behaviors, and beliefs concerning their well-being. Community-based participatory research takes into account the strengths and insights that community and academic partners bring to framing health problems and developing solutions. Not all research that is conducted in communities (community-placed research) is participatory in nature. Rather, CBPR and related approaches to community-engaged research occur across a continuum, as discussed in chapter 2 by Steven Coughlin and Wonsuk Yoo. In its purest form, CBPR involves true partnerships between academic researchers and community members.

This book on CBPR is an important addition to Oxford University Press’s outstanding line of books on public health and related topics because of

widespread interest in CBPR; health disparities; public health research involving racial and ethnic minority communities; the health of immigrants; women's health; maternal and child health; infant mortality; cancer screening; prevention of cardiovascular disease, hypertension, obesity, and diabetes; cigarette smoking, physical activity, and diet; HIV/AIDS prevention; faith-based health interventions; gay, lesbian, bisexual, and transgender health; mental health; substance abuse; sexual assault and violence; urban health; rural health; environmental health and environmental justice; global health; research ethics; and public health ethics. This volume complements and explicates closely related developments such as community-based evaluative research, community-engaged research, and the National Institutes of Health (NIH) Clinical and Translational Science Awards.

This book is likely to be a useful resource for public health researchers, practitioners, and members of communities who are challenged by health disparities. This book will be of interest to practicing public health professionals from various public health disciplines (epidemiology, behavioral science, health communications, community engagement, nutrition, environmental health, health disparities, and global health) and to members of nonprofit organizations, community-based organizations, and members of community coalitions and health advocacy organizations. Many contributors to this book are nationally and internationally recognized for their work. The chapters were contributed by experts from a variety of backgrounds and disciplines. Notably, several of the authors who contributed to this volume are members of community-based organizations, community coalitions, and nonprofit organizations in the United States, Canada, Great Britain, and Switzerland. While editing this book with his coeditors, Steven Coughlin served as a member of both the Connect-to-Protect community coalition on HIV/AIDS among young people in Memphis, Tennessee, and the Mayor's Health Task Force Healthy Active Living Working Group in Lawrence, Massachusetts. Maria Fernandez was founder of Latinos in a Network for Cancer Control (LINCC) in Texas.

We are grateful to our families and close friends who supported us in this multiple-year effort. We would thank Chad Zimmerman, our editor with Oxford University Press, and his assistant Chloe Layman. In addition, we are grateful to our professional colleagues and students at the Rollins School of Public Health at Emory University (S.S.C.); the University of Tennessee College of Medicine Department of Preventive Medicine (S.S.C.); the University of Massachusetts Lowell Division of Public Health (S.S.C.); the University of Massachusetts Center for Clinical and Translational Sciences (S.S.C.); the Augusta University College of Health Sciences (S.S.C.); the Institute for Public and Preventive Health at the University of Augusta (S.A.S.); the Department of Family Medicine at the Medical College of Augusta (S.A.S.); and the University of Texas at Houston School of

Public Health (M.E.F.). Selina Smith was supported by a grant awarded to the Augusta University Institute of Public and Preventive Health by the National Cancer Institute (R01CA166785).

S.S.C.
Augusta, Georgia

S.A.S.
Augusta, Georgia

M.E.F.
Houston, Texas

Contributors

Leland K. Ackerson, ScD, MPH

Graduate Public Health Program
Coordinator
Associate Professor
Department of Community Health
and Sustainability
University of Massachusetts, Lowell
Lowell, Massachusetts

Tobia Henry Akintobi, PhD, MPH

Associate Professor and Associate
Dean, Community Engagement
Director, Prevention Research Center
Director, Evaluation and Institutional
Assessment
Associate Professor
Department of Community Health
and Preventive Medicine
Morehouse School of Medicine
Atlanta, Georgia

Benjamin E. Ansa, MD, MSCR

Senior Research Associate
Institute of Public and
Preventive Health
Augusta University
Augusta, Georgia

Peter Baltrus, PhD

Associate Professor of Community
Health and Preventive Medicine
National Center for Primary Care
Morehouse School of Medicine
Atlanta, Georgia

Shanice Battle, MPH

Department of Psychiatry
Center for Maternal Substance Abuse
and Child Development
Emory University School of Medicine
Atlanta, Georgia

Allyson S. Belton, MPH

Associate Project Director
Satcher Health Leadership Institute
Morehouse School of Medicine
Atlanta, Georgia

Mara Bird, PhD

Director
Center for Latino Community
Health, Evaluation and Leadership
Training
California State University,
Long Beach
Long Beach, California

Daniel Blumenthal, MD, MPH

President, American College of
Preventive Medicine
Professor Emeritus
Department of Community Health
and Preventive Medicine
Morehouse School of Medicine
Atlanta, Georgia

Deborah Bowen, PhD

Professor
Department of Bioethics and
Humanities
School of Medicine
University of Washington
Seattle, Washington

Ulrike Brizay, PhD

University of Applied Science, FH
Erfurt, Germany

Steven S. Coughlin, PhD

Associate Professor
Department of Clinical and Digital
Health Sciences
College of Allied Health Sciences
Augusta University
Augusta, Georgia
Adjunct Professor
of Epidemiology
Rollins School of Public Health
Emory University
Atlanta, Georgia

Pamela Daniels, MBA, MPH, PhD

Epidemiologist
Morehouse School of Medicine
Atlanta, Georgia

Maria E. Fernandez, PhD

Director, Center for Health Promotion
and Prevention Research
University of Texas at Houston, School
of Public Health
Professor, Health Promotion and
Behavioral Sciences
Houston, Texas

Maria Eugenia

Fernandez-Esquer, PhD

Associate Professor of Health
Promotion and Behavioral
Sciences
University of Texas Health Science
Center at Houston, School of
Public Health
Houston, Texas

Jennifer Glick, PhD, MPH

Department of Global Community
Health and Behavioral Sciences
School of Public Health and Tropical
Medicine
Tulane University
New Orleans, Louisiana

Jason Globberman, MSc

Ontario HIV Treatment Network
Toronto, Canada

David Gogolishvili, MPH

Ontario HIV Treatment Network
Toronto, Canada

Lina Golob, MSc

International AIDS Society
Geneva, Switzerland

Erin N. Haynes, DrPH, MS

Associate Professor
Director, Clinical and Translational
Research Training Program
Director, Community Outreach and
Engagement Core, Center for
Environmental Genetics
Division of Epidemiology
Department of Environmental Health
University of Cincinnati, College of
Medicine
Cincinnati, Ohio

Shirin Heidari, PhD

Director
Reproductive Health Matters
London, United Kingdom

Harry J. Heiman, MD, MPH

Director, Division of Health Policy
Satcher Health Leadership Institute
Morehouse School of Medicine
Atlanta, Georgia

Natalia I. Heredia, MPH

Predoctoral fellow, PhD candidate
University of Texas Health Science
Center at Houston, School of
Public Health
Houston, Texas

LaShawn M. Hoffman

Chair, Community Coalition Board
Prevention Research Center
Morehouse School of Medicine
Atlanta, Georgia

Kisha B. Holden, PhD, MSCR

Associate Professor, Department of
Psychiatry and Behavioral Sciences
Department of Community Health
and Preventive Medicine
Interim Director, Satcher Health
Leadership Institute
Morehouse School of Medicine
Atlanta, Georgia

Cheryl L. Holt, PhD

Associate Professor, Behavioral and
Community Health
Director, CHAMP (Community
Health Awareness, Messages, and
Prevention) Lab
Codirector, Center for Health Behavior
Research
Coleader for Population Science Program
in the Greenebaum Cancer Center
University of Maryland
College Park, Maryland

Farrah Jacquez, PhD

Associate Professor
Department of Psychology
University of Cincinnati
Cincinnati, Ohio

**Carolyn M. Jenkins, DrPH, MSN,
RN, RD, LD, FAAN**

Professor and Ann Darlington
Edwards Endowed Chair in
Nursing
Director for Center for Community
Health Partnerships
Codirector, SCTR Community
Engagement
Medical University of South Carolina
Charleston, South Carolina

Carl Kendall, PhD

Director, Center for Global
Health Equity
Professor, Department of Global
Community Health and Behavioral
Sciences
School of Public Health and Tropical
Medicine
Tulane University
New Orleans, Louisiana

Stephani S. Kim, MPH

Doctoral Student
Division of Epidemiology
Department of Environmental
Health
University of Cincinnati, College of
Medicine
Cincinnati, Ohio

Heather Kitzman-Ulrich, PhD

Director, Research and Development
Diabetes Health & Wellness Institute
Baylor Scott and White Health
Dallas, Texas
Adjunct Assistant Professor
Department of Behavioral and
Community Health
School of Public Health
University of North Texas Health
Science Center
Fort Worth, Texas

Yen-Chi L. Le, PhD

Project Manager II, Adjunct Faculty
Healthcare Transformation Initiatives
Department
University of Texas Health Science
Center at Houston, McGovern
Medical School
Houston, Texas

Rodney Lyn, PhD, MS

Associate Professor and Associate
Dean for Academic Affairs
School of Public Health
Georgia State University
Atlanta, Georgia

Kelly G. McGauhey

Center for Health Promotion and
Prevention Research
University of Texas Health Science
Center at Houston, School of
Public Health
Houston, Texas

Annie L. Nguyen, PhD, MPH

Assistant Professor
Department of Family Medicine
Keck School of Medicine
University of Southern California
Los Angeles, California

Tonny J. Oyana, PhD

Director of Spatial Analytics and
Informatics Core,
Research Center for Health
Disparities, Equity, and the
Exposome
Professor, Department of Preventive
Medicine
University of Tennessee Health
Science Center
Memphis, Tennessee

Britt Riot-Ellis, PhD

Founding Dean
College of Health Science and Human
Services
California State University,
Monterey Bay
Seaside, California

Latrice Rollins, PhD, MSW

Assistant Director of Evaluation and
Institutional Assessment
Prevention Research Center
Department of Community Health
and Preventive Medicine
Morehouse College of Medicine
Atlanta, Georgia

Sean B. Rourke, PhD, FCAHS

Scientific and Executive Director
Ontario HIV Treatment Network
Professor of Psychiatry
University of Toronto
Scientist, Li Ka Shing Knowledge
Institute of St. Michael's Hospital
Toronto, Canada

David Seal, PhD

Professor and Vice-Chair
Doctoral Programs Director
Department of Global Community
Health and Behavioral Sciences
School of Public Health and Tropical
Medicine
Tulane University
New Orleans, Louisiana

Selina A. Smith, PhD, MDiv

Director, Institute of Public and
Preventive Health
Professor and Curtis G. Hames, MD,
Distinguished Chair
Department of Family Medicine,
Medical College of Georgia
Augusta, Georgia

Lisa M. Vaughn, PhD

Professor, Pediatrics
Cincinnati Children's Hospital
Medical Center
University of Cincinnati College of
Medicine
Cincinnati, Ohio

Alice Welbourn, PhD

Founding Director
Salamander Trust
London, United Kingdom

Glenda Wrenn, MD, MSHP

Assistant Professor
Department of Psychiatry and
Behavioral Sciences
Morehouse School of Medicine
Atlanta, Georgia

Wonsuk Yoo, PhD

Associate Director, Data
Coordinating Center
Institute of Public and
Preventive Health
Associate Professor
College of Dental Medicine
Augusta University
Augusta, Georgia

Emily Youngblom, MPH

Institute of Public Health
Genetics
University of Washington
Seattle, Washington

Contents

Preface ix

Contributors xiii

1. Overview of Community-Based Participatory Research 1

STEVEN S. COUGHLIN, PHD, SELINA A. SMITH, PHD, MDIV, AND
MARIA E. FERNANDEZ, PHD

2. Community-Based Participatory Research Study Approaches Along a Continuum of Community-Engaged Research 11

STEVEN S. COUGHLIN, PHD AND WONSUK YOO, PHD

3. Research Methods and Community-Based Participatory Research: Challenges and Opportunities 21

CARL KENDALL, PHD, ANNIE L. NGUYEN, PHD, MPH,
JENNIFER GLICK, PHD, MPH, AND DAVID SEAL, PHD

4. The Use of GIS/GPS and Spatial Analyses in Community-Based Participatory Research 39

TONNY J. OYANA, PHD

5. Ethical Issues in Community-Based Participatory Research Studies 57

STEVEN S. COUGHLIN, PHD AND LELAND K. ACKERSON, SCD

6. Community-Based Participatory Research Studies in Faith-Based Settings 71

HEATHER KITZMAN-ULRICH, PHD AND CHERYL L. HOLT, PHD

7. Special Issues in Conducting Community-Based Participatory Research Studies with Ethnic and Racial Minorities 81
 MARIA E. FERNANDEZ, PHD, NATALIA I. HEREDIA, MPH, LORNA H. MCNEILL, PHD, MPH, MARIA EUGENIA FERNANDEZ-ESQUER, PHD, YEN-CHI L. LE, PHD, AND KELLY G. MCGAUHEY, BS
8. Community-Based Participatory Research Studies Involving Immigrants 115
 LISA M. VAUGHN, PHD AND FARRAH JACQUEZ, PHD
9. Applying a Community-Based Participatory Research Approach to Address Determinants of Cardiovascular Disease and Diabetes Mellitus in an Urban Setting 131
 TOBIA HENRY AKINTOBI, PHD, MPH, KISHA B. HOLDEN, PHD, MSCR, LATRICE ROLLINS, PHD, MSW, RODNEY LYN, PHD, MPH, HARRY J. HEIMAN, MD, MPH, PAMELA DANIELS, PHD, MBA, GLENDA WRENN, MD, ALLYSON S. BELTON, MPH, PETER BALTRUS, PHD, SHANICE BATTLE, MPH, AND LASHAWN M. HOFFMAN
10. Community-Based Participatory Research Addressing Infant Mortality 155
 STEVEN S. COUGHLIN, PHD AND SELINA A. SMITH, PHD, MDIV
11. Colorectal Cancer Disparities and Community-Based Participatory Research 167
 SELINA A. SMITH, PHD, MDIV, BENJAMIN E. ANSA, MD, MSCR, AND DANIEL S. BLUMENTHAL, MD, MPH
12. Community-Based Participatory Research Studies on Breast and Cervical Cancer Screening 185
 STEVEN S. COUGHLIN, PHD, EMILY YOUNGBLOM, MPH, AND DEBORAH J. BOWEN, PHD
13. Overview of Community-Based Participatory Research in Environmental Health 205
 STEPHANI S. KIM, MPH AND ERIN N. HAYNES, DRPH, MS
14. Community-Based Participatory Research Studies on Interpersonal Violence: Ending the Cycle of Poverty and Violence 223
 STEVEN S. COUGHLIN, PHD

15. Using Community-Based Participatory Research
Approaches in HIV: Three Case Studies 235

MARA BIRD, PHD, BRITT RIOS-ELLIS, PHD, JASON GLOBERMAN,
MSC, DAVID GOGOLISHVILI, MPH, ALICE WELBOURN, PHD,
ULRIKE BRIZAY, PHD, LINA GOLOB, MSC, SHIRIN HEIDARI, PHD,
AND SEAN B. ROURKE, PHD, FCAHS

16. Engaging Communities in Translational Research 251

STEVEN S. COUGHLIN, PHD AND CAROLYN M. JENKINS,
DRPH, MSN, RN, RD, LD, FAAN

17. Summary and Conclusions 267

STEVEN S. COUGHLIN, PHD

Index 277

Overview of Community-Based Participatory Research

STEVEN S. COUGHLIN, PHD, SELINA A. SMITH, PHD, MDIV,
AND MARIA E. FERNANDEZ, PHD

This chapter provides an introduction to community-based participatory research (CBPR), a collaborative approach to research that equitably involves all partners, including community members affected by the health topic being addressed, organizational representatives, and academic researchers, in the research process. This approach includes partnerships between academic and community organizations with the goal of increasing the value of the research product for all partners and sustaining its impact on population health. Community-based participatory research addresses health disparities and inequities in diverse communities including groups that are socially disadvantaged, marginalized, stigmatized, or that have suffered historical injustices. It takes into account the strengths and insights that community and academic partners bring to framing health problems and developing solutions. As illustrated throughout this volume, CBPR approaches have been used to address a wide variety of health topics, including environmental hazards, HIV/AIDS, maternal and child health, cancer, cardiovascular disease, diabetes, obesity, cigarette smoking, substance abuse, and mental health. The combination of experiences of community members with public health science provides a deeper understanding of complex social phenomena, thereby providing more relevant interventions and increasing the likelihood that the interventions will be effective and that they will be adopted, implemented, and sustained in real-world settings. The CBPR research paradigm represents a fundamental shift in academic researchers' views of community residents, from patients and research subjects who may benefit from medical advances to essential partners who can energize their communities to develop and implement effective, sustainable interventions to improve health and eliminate health disparities.

What Is Community-Based Participatory Research?

Community-based participatory research is a collaborative approach to research in which the research process is driven by an equitable partnership that is formed between relevant community members, organizational representatives, and academic researchers; the CBPR framework uses this partnership with the aim of increasing the value of the research product for all partners. Community-based participatory research takes advantage of the unique strengths and insights that community and academic partners each bring to framing health problems and developing solutions. Community members, organizational representatives, and academic researchers participate in and share control over all phases of the research process from assessment—discovering the community's health needs—to dissemination—developing strategies to increase the adoption, implementation, and maintenance of evidence-based interventions (EBIs) in communities and healthcare settings. Community-based participatory research approaches facilitate and accelerate research translation so that research produces pragmatic results capable of leading to positive and sustainable community change.

In the past, social scientists and researchers who focused on disease prevention tended to engage in studies of social phenomena and community problems with an “outsider’s approach,” which distanced the research from the participants’ daily lives. Lewin¹ and Freire² questioned the “outsider’s approach” and proposed more participatory and inclusive approaches to research. Current perspectives seek to address the complexity of the human experience and the differential power that sometimes exists between academic researchers, representatives of community groups, and research participants.

“The CBPR research paradigm represents a fundamental shift in academic researcher’s views of community residents, from patients and research subjects who may benefit from medical advances to essential partners who can energize their communities to develop effective, sustainable interventions to improve health and eliminate health disparities.”³

Rather than focusing solely on health problems or other concerns, the CBPR framework highlights community resilience, resources, and opportunities for positive growth.⁴ It places emphasis on shared decision-making, co-learning, reciprocal transfer of expertise between partners, and mutual ownership of research products.⁵ Partners also strive to acknowledge and act on participants’ needs, behaviors, and beliefs concerning their own well-being. Community-based participatory research is linked to other social-justice-informed approaches to research, such as action research and participatory action research, that empower communities to address the root causes of inequity and identify their own problems and appropriate solutions; thus CBPR efforts typically do not focus on the individual only. Instead, CBPR fits within an ecological perspective about the determinants

of adverse health outcomes and includes consideration of individual-level risk factors, multiple social determinants of health, and structural problems such as poverty, unemployment, homophobia/transphobia, racism, and lack of access to primary healthcare.

PROCESS

The starting point for a CBPR project typically includes a health needs assessment, a focused literature review, and a review of published and unpublished data to identify priority health concerns. Epidemiologic data about the geographic and social distribution and determinants of health concerns in a community are also useful for planning purposes. For example, such data may include age-adjusted morbidity and mortality rates at the zip code or county level broken down by race, ethnicity, or other factors, or geospatial information about educational attainment, household income, or the availability of primary healthcare and public transportation. The needs assessment process should be carried out using the same principles of CBPR as all other phases of the research effort. Gathering community member feedback can be done through a variety of methods, such as obtaining information through in-depth interviews of key informants or soliciting feedback during community advisory board meetings. Including community representatives as integral members of the planning group, however, helps ensure participation throughout the planning process. Planning groups including community partners should explore existing sources of data and the need for new data collection and should participate collaboratively in the interpretation of findings.⁶ The CBPR approach requires academic researchers to listen to the voices of community residents before a shared decision is made about which health topics to address first. Thus, although seat belt use may be an important public health concern in a community, and an academic researcher may wish to compete for funding for a study of the effectiveness of an intervention to increase seat belt use, community residents and representatives of community organizations may give priority to projects that address breast cancer screening and survival among African American women or disparities in infant mortality by race, ethnicity, or socioeconomic status.

The importance of addressing community priorities is emphasized in a definition of CBPR provided by the Kellogg Foundation Community Health Scholars Program. According to this definition, CBPR “equitably involves all partners with a research topic of importance to the community with the aim of contributing knowledge and action for social change to improve community health and eliminate health disparities.”

Several principles of CBPR have been identified: the need to ensure openness, trust, and power sharing among partners; the need for a genuine partnership approach; capacity-building of community partners; and the importance of shared decision-making, colearning, shared ownership of research products, applying