

EDITED BY

IRENE DANKWA-MULLAN, MD, MPH

ELISEO J. PÉREZ-STABLE, MD

KEVIN L. GARDNER, MD, PhD

XINZHI ZHANG, MD, PhD, FACE, FRSM

ADELAIDA M. ROSARIO, PhD



THE SCIENCE OF HEALTH DISPARITIES RESEARCH



WILEY Blackwell

The Science of Health Disparities Research

The Science of Health Disparities Research

Edited by

Irene Dankwa-Mullan

IBM Watson Health

IBM Corporation

Bethesda, MD, USA

Eliseo J. Pérez-Stable

National Institute on Minority Health and Health Disparities

National Institutes of Health

Bethesda, MD, USA

Kevin L. Gardner

Department of Pathology and Cell Biology

Columbia University Medical Center

New York, NY, USA.

Xinzhi Zhang

*Division of Clinical Innovation, National Center for Advancing
Translational Science*

National Institutes of Health

Bethesda, MD, USA

Adelaida M. Rosario

Commissioned Corps Headquarters

Office of the Surgeon General

Rockville, MD, USA

WILEY Blackwell

This edition first published 2021
© 2021 John Wiley & Sons, Inc.

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, electronic, mechanical, photocopying, recording or otherwise, except as permitted by law. Advice on how to obtain permission to reuse material from this title is available at <http://www.wiley.com/go/permissions>.

The right of Irene Dankwa-Mullan, Eliseo J. Pérez-Stable, Kevin L. Gardner, Xinzhi Zhang, Adelaida M. Rosario to be identified as the author(s) of the editorial material in this work has been asserted in accordance with law.

Registered Office

John Wiley & Sons, Inc., 111 River Street, Hoboken, NJ 07030, USA

Editorial Office

9600 Garsington Road, Oxford, OX4 2DQ, UK

For details of our global editorial offices, customer services, and more information about Wiley products visit us at www.wiley.com.

Wiley also publishes its books in a variety of electronic formats and by print-on-demand. Some content that appears in standard print versions of this book may not be available in other formats.

Limit of Liability/Disclaimer of Warranty

While the publisher and authors have used their best efforts in preparing this work, they make no representations or warranties with respect to the accuracy or completeness of the contents of this work and specifically disclaim all warranties, including without limitation any implied warranties of merchantability or fitness for a particular purpose. No warranty may be created or extended by sales representatives, written sales materials or promotional statements for this work. The fact that an organization, website, or product is referred to in this work as a citation and/or potential source of further information does not mean that the publisher and authors endorse the information or services the organization, website, or product may provide or recommendations it may make. This work is sold with the understanding that the publisher is not engaged in rendering professional services. The advice and strategies contained herein may not be suitable for your situation. You should consult with a specialist where appropriate. Further, readers should be aware that websites listed in this work may have changed or disappeared between when this work was written and when it is read. Neither the publisher nor authors shall be liable for any loss of profit or any other commercial damages, including but not limited to special, incidental, consequential, or other damages.

Library of Congress Cataloging-in-Publication Data

Names: Dankwa-Mullan, Irene, editor. | Pérez-Stable, Eliseo J., editor. | Gardner, Kevin L., M.D., editor. | Zhang, Xinzhi, 1971– editor. | Rosario, Adelaida M., 1977– editor.

Title: The science of health disparities research / edited by Irene Dankwa-Mullan, Eliseo J. Pérez-Stable, Kevin L. Gardner, Xinzhi Zhang, Adelaida M. Rosario.

Description: Hoboken, NJ : Wiley-Blackwell, 2021. | Includes bibliographical references and index.

Identifiers: LCCN 2020024358 (print) | LCCN 2020024359 (ebook) | ISBN 9781119374817 (cloth) | ISBN 9781119374831 (adobe pdf) | ISBN 9781119374848 (epub)

Subjects: MESH: Healthcare Disparities | Translational Medical Research | Socioeconomic Factors | Social Determinants of Health | Minority Health
Classification: LCC RA563.M56 (print) | LCC RA563.M56 (ebook) | NLM W 76.1 | DDC 362.1089–dc23

LC record available at <https://lcn.loc.gov/2020024358>

LC ebook record available at <https://lcn.loc.gov/2020024359>

Cover Design: Wiley

Cover image: Barbershop Photo Courtesy of Stephen B. Thomas, Hula Dance Photo Courtesy of Joseph Kaholokula, Happy Baby Girl Playing With Toys In Playroom © Monkey Business Images/Shutterstock

Set in 9.5/12.5pt STIXTwoText by SPi Global, Pondicherry, India

Contents

- List of Contributors** ix
- Foreword** xxi
- Acknowledgements** xxiii
- 1 Definitions, Principles, and Concepts for Minority Health and Health Disparities Research** 1
Eliseo J. Pérez-Stable, Jennifer Alvidrez, and Carl V. Hill
 - 2 Getting Under the Skin: Pathways and Processes that Link Social and Biological Determinants of Disease** 13
Chandra L. Jackson, Rada K. Dagher, Jung S. Byun, Tilda Farhat, and Kevin L. Gardner
 - 3 Racial/Ethnic, Socioeconomic, and Other Social Determinants** 39
Tiffany L. Gary-Webb, Sara E. Baumann, Erik J. Rodriguez, Lydia A. Isaac, and Thomas A. LaVeist
 - 4 Behavioral Determinants in Population Health and Health Disparities Research** 59
Amelie G. Ramirez, Patricia Chalela, Melanie D. Sabado-Liwag, and Kelvin Choi
 - 5 Sociocultural Environments and Health Disparities Research: Frameworks, Methods, and Promising Directions** 77
Hortensia Amaro, Samantha Garcia, Inna Arnaudova, and Monica P. Jolles
 - 6 Physical Environment, and Minority Health and Health Disparities Research** 95
Tracy Bastain, Carrie Breton, Shohreh Farzan, Rima Habre, Jill Johnston, Derrick C. Tabor, Claudia Toledo-Corral, and Elizabeth Vang
 - 7 Genome-wide Genetic Approaches to Metabolic and Inflammatory Health Disparities** 109
Cheryl A. Winkler

- 8 Biologic Factors and Molecular Determinants in Inflammatory and Metabolic Diseases** 125
Marquitta White, Esteban Burchard, Page Goddard, Anup K. Nair, Leslie J. Baier, Federico Fuentes, and Jeffrey B. Kopp
- 9 Insights into the Genomic Landscape of African Ancestry Populations: Implications for Health and Disease Disparities** 139
Charles N. Rotimi, Amy R. Bentley, Ayo P. Doumatey, Guanjie Chen, Daniel Shriner, and Adebawale Adeyemo
- 10 Applying Self-report Measures in Minority Health and Health Disparities Research** 153
Mariana Sanchez, Bertha Hidalgo, Adelaida Rosario, Ligia Artilles, Anita L. Stewart, and Anna M. Nápoles
- 11 Conducting Community-based Participatory Research with Minority Communities to Reduce Health Disparities** 171
Tung T. Nguyen, Nina Wallerstein, Rina Das, Melanie D. Sabado-Liwag, Valarie Blue Bird Jernigan, Tvli Jacob, Tamela Cannady, Linda Sprague Martinez, Uchenna J. Ndulue, Abigail Ortiz, Andrea Williams Stubbs, Latrice C. Pichon, Sora Park Tanjasiri, Jane Pang, and Kent Woo
- 12 Racial/Ethnic Health and Healthcare Disparities Measurement: The Application of the Principles and Methods of Causal Inference** 187
Benjamin Cook, Sarah Forrester, Timothy Creedon, Joan Wasserman, Meryl Sufian, and Jeroan Allison
- 13 Small Area Estimation and Bayesian Disease Mapping for Minority Health and Health Disparities** 203
Xingyou Zhang, Benmei Liu, Shumei Yun, and Robert L. Phillips
- 14 Applications of Big Data Science and Analytic Techniques for Health Disparities Research** 221
Irene Dankwa-Mullan, Xinzhi Zhang, Phuong-Tu Le, and William T. Riley
- 15 Complex Systems Science** 243
Matt Kasman, Nancy Breen, and Ross A. Hammond
- 16 Improving Equity in Healthcare through Multilevel Interventions** 257
Margarita Alegria, Jacqueline J. Lloyd, Naomi Ali, and Karissa DiMarzio
- 17 Using Implementation Science to Move from Knowledge of Disparities to Achievement of Equity** 289
Lisa A. Cooper, Tanjala S. Purnell, Michael Engelgau, Kristina Weeks, and Jill A. Marsteller

- 18 Healthcare and Public Policy: Challenges and Opportunities for Research** 309
Olveen Carrasquillo, Sonjia Kenya, Stuti Dang, Cynthia Lebron, and Tilda Farhat
- 19 Addressing Disparities in Access to High-quality Care** 321
Milda Saunders, Regina James, Kesi Williams, and Marshall Chin
- 20 Health Communication as a Mediator of Health and Healthcare Disparities** 339
Neda Ratanawongsa, Benyam Hailu, and Dean Schillinger
- 21 Comparative Effectiveness Research in Health Disparity Populations** 359
William V. Padula, Rick A. Berzon, Priscah Mujuru, and David O. Meltzer
- 22 The Role of Electronic Health Records and Health Information Technology in Addressing Health Disparities** 375
Irene Dankwa-Mullan, Sherine El-Toukhy, Jessamine Winer-Jones, Nora Haney, Morgan Foreman, Kesi Williams, and Anil Jain
- 23 Precision Medicine and Health Disparities** 391
Consuelo H. Wilkins, Nancy J. Cox, Sarah C. Stallings, Maria F. Lima, Roy E. Weiss, and Nishadi Rajapakse
- 24 Recruitment, Inclusion, and Diversity in Clinical Trials** 413
Bernadette Boden-Albala, Salina P. Waddy, Noa Appleton, Heather Kuczynski, Emily Nangle, and Nina S. Parikh
- 25 Sexual and Gender Minority Health Disparities: Concepts, Methods, and Future Directions** 429
Mark L. Hatzenbuehler and John E. Pachankis
- 26 Workforce Diversity and Capacity Building to Address Health Disparities** 445
Hannah A. Valentine and Alison F. Davis
- Index** 455

List of Contributors

Adebowale Adeyemo

Center for Research on Genomics and
Global Health, National Human Genome
Research Institute,
National Institutes of Health
Bethesda, MD
USA

Margarita Alegria

Department of Medicine, Disparities of
Research Unit
Massachusetts General Hospital
Boston, MA
USA;
Departments of Medicine and Psychiatry
Harvard Medical School
Boston, MA
USA

Naomi Ali

Department of Medicine, Disparities of
Research Unit
Massachusetts General Hospital
Boston, MA
USA

Jeroan Allison

University of Massachusetts
Medical School
Worcester, MA
USA

Jennifer Alvidrez

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Hortensia Amaro

Herbert Wertheim, College of Medicine
Florida International University
Miami, FL
USA;
Robert Stempel, College of Public Health
and Social Work
Florida International University
Miami, FL
USA

Noa Appleton

Department of Population Health
New York University School of
Medicine
New York, NY
USA

Inna Arnaudova

Department of Psychiatry
University of California
Los Angeles, CA
USA

Ligia Artiles

National Institute on Minority Health and Health Disparities
National Institutes of Health
Bethesda, MD
USA

Leslie J. Baier

Phoenix Epidemiology and Clinical Research Branch, National Institute of Diabetes and Digestive and Kidney Diseases
National Institutes of Health
Phoenix, AZ
USA

Tracy Bastain

Department of Preventive Medicine, Keck School of Medicine
University of Southern California
Los Angeles, CA
USA

Sara E. Baumann

Department of Behavioral and Community Health Sciences
University of Pittsburgh Graduate School of Public Health
Pittsburgh, PA
USA

Amy R. Bentley

Center for Research on Genomics and Global Health, National Human Genome Research Institute
National Institutes of Health
Bethesda, MD
USA

Rick A. Berzon

National Institute on Minority Health and Health Disparities
National Institutes of Health
Bethesda, MD
USA

Bernadette Boden-Albala

Department of Population Health and Disease Prevention
University of California
Irvine, CA
USA;
Department of Epidemiology
University of California
Irvine, CA
USA

Nancy Breen

National Institute on Minority Health and Health Disparities
National Institutes of Health
Bethesda, MD
USA

Carrie Breton

Department of Preventive Medicine, Keck School of Medicine
University of Southern California
Los Angeles, CA
USA

Esteban Burchard

Department of Bioengineering and Therapeutic Sciences
University of California
San Francisco, CA
USA

Jung S. Byun

National Institute on Minority Health and Health Disparities
National Institutes of Health
Bethesda, MD
USA

Tamela Cannady

Choctaw Nation Health Service
Talihina, OK
USA

Olveen Carrasquillo

Division of General Internal Medicine,
Department of Medicine, Miller School of
Medicine
University of Miami
Miami, FL
USA

Patricia Chalela

Institute for Health Promotion Research
University of Texas Health Science Center
San Antonio, TX
USA

Guanjie Chen

Center for Research on Genomics and
Global Health, National Human Genome
Research Institute
National Institutes of Health
Bethesda, MD
USA

Marshall Chin

Department of Medicine
The University of Chicago
Chicago, IL
USA

Kelvin Choi

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Benjamin Cook

Harvard Medical School
Boston, MA
USA;
Cambridge Health Alliance
Cambridge, MA
USA

Lisa A. Cooper

Johns Hopkins Center for Health
Equity
Johns Hopkins University
Baltimore, MD
USA

Nancy J. Cox

Vanderbilt Genetics Institute, Department
of Medicine, Division of Genetic
Medicine
Vanderbilt University Medical Center
Nashville, TN
USA

Timothy Creedon

Cambridge Health Alliance
Cambridge, MA
USA

Rada K. Dagher

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Irene Dankwa-Mullan

IBM Watson Health
International Business Machines (IBM)
Corporation
Bethesda, MD
USA

Stuti Dang

Division of Geriatrics, Department of
Medicine, Miller School of Medicine
University of Miami
Miami, FL
USA

Rina Das

National Institute on Minority Health and Health Disparities
National Institutes of Health
Bethesda, MD
USA

Alison F. Davis

Scientific Workforce Diversity, Office of the Director
National Institutes of Health
Bethesda, MD
USA

Karissa DiMarzio

Department of Medicine, Disparities of Research Unit
Massachusetts General Hospital
Boston, MA
USA

Ayo P. Doumatey

Center for Research on Genomics and Global Health, National Human Genome Research Institute
National Institutes of Health
Bethesda, MD
USA

Sherine El-Toukhy

National Institute on Minority Health and Health Disparities
National Institutes of Health
Bethesda, MD
USA

Michael Engलगau

National Heart, Lung, and Blood Institute
National Institutes of Health
Bethesda, MD
USA

Tilda Farhat

National Institute on Minority Health and Health Disparities

National Institutes of Health
Bethesda, MD
USA

Shohreh Farzan

Department of Preventive Medicine, Keck School of Medicine
University of Southern California
Los Angeles, CA
USA

Morgan Foreman

Center for Computational Health & Integrated Care Research, IBM Research International Business Machines (IBM) Corporation
Cambridge, MA
USA

Sarah Forrester

University of Massachusetts
Medical School
Worcester, MA
USA

Federico Fuentes

Kidney Diseases Branch, National Institute of Diabetes and Digestive and Kidney Diseases,
National Institutes of Health
Bethesda, MD
USA

Samantha Garcia

Program in Public Health
University of California
Irvine, CA
USA

Kevin L. Gardner

Department of Pathology and Cell Biology
Columbia University Medical Center
New York, NY
USA

Tiffany L. Gary-Webb

Department of Behavioral and Community
Health Sciences
University of Pittsburgh Graduate School
of Public Health
Pittsburgh, PA
USA;

Department of Epidemiology
University of Pittsburgh Graduate School
of Public Health
Pittsburgh, PA
USA

Page Goddard

Department of Bioengineering and
Therapeutic Sciences
University of California
San Francisco, CA
USA

Rima Habre

Department of Preventive Medicine, Keck
School of Medicine
University of Southern California
Los Angeles, CA
USA

Benyam Hailu

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Ross A. Hammond

Center on Social Dynamics and Policy
Brookings Institution
Washington, DC
USA;
Brown School
Washington University in St. Louis
St. Louis, MO
USA

Nora Haney

The James Buchanan Brady Urological
Institute
Johns Hopkins Hospital
Baltimore, MD
USA

Mark L. Hatzenbuehler

Department of Psychology
Harvard University
Cambridge, MA
USA

Bertha Hidalgo

Ryals School of Public Health
The University of Alabama at
Birmingham
Birmingham, AL
USA

Carl V. Hill

Office of Special Populations, National
Institute of Aging
National Institutes of Health
Bethesda, MD
USA

Lydia A. Isaac

Department of Health Policy and
Management, Milken Institute School of
Public Health
The George Washington University
Washington, DC
USA

Chandra L. Jackson

Epidemiology Branch, Social and
Environmental Determinants of
Health Equity, National Institute of
Environmental Health Sciences
National Institutes of Health
Cary, NC
USA

Tvli Jacob

Center for Health Sciences
Oklahoma State University
Tulsa, OK
USA

Anil Jain

IBM Watson Health
International Business Machines (IBM)
Corporation
Cleveland, OH
USA

Regina James

2M Research
Arlington, VA
USA

Valarie Blue Bird Jernigan

Center for Health Sciences
Oklahoma State University
Tulsa, OK
USA

Jill Johnston

Department of Preventive Medicine, Keck
School of Medicine
University of Southern California
Los Angeles, CA
USA

Monica P. Jolles

Suzanne Dworak-Peck, School of
Social Work
University of Southern California
Los Angeles, CA
USA;
Cecil G. Sheps Center for Health Services
Research
University of North Carolina
Chapel Hill, NC
USA

Matt Kasman

Center on Social Dynamics and Policy
Brookings Institution
Washington, DC
USA

Sonjia Kenya

Division of General Internal Medicine,
Department of Medicine, Miller School of
Medicine
University of Miami
Miami, FL
USA

Jeffrey B. Kopp

Kidney Diseases Branch, National Institute
of Diabetes and Digestive and Kidney
Diseases,
National Institutes of Health
Bethesda, MD
USA

Heather Kuczynski

School of Global Public Health
New York University
New York, NY
USA

Thomas A. LaVeist

Tulane University School of Public Health
and Tropical Medicine
New Orleans, LA
USA

Phuong-Tu Le

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Cynthia Lebron

School of Nursing and Health Studies
University of Miami
Coral Gables, FL
USA

Maria F. Lima

CUNY School of Medicine
The City College of New York
New York, NY
USA

Benmei Liu

National Cancer Institute
National Institutes of Health
Bethesda, MD
USA

Jacqueline J. Lloyd

National Institute on Drug Abuse
National Institutes of Health
Rockville, MD
USA

Jill A. Marsteller

Johns Hopkins Center for Health Equity
Johns Hopkins University
Baltimore, MD
USA

Linda Sprague Martinez

School of Social Work
Boston University
Boston, MA
USA

David O. Meltzer

Department of Medicine
The University of Chicago
Chicago, IL
USA

Priscah Mujuru

National Institute on Minority Health and
Health Disparities
National Institutes of Health

Bethesda, MD
USA

Anup K. Nair

Phoenix Epidemiology and Clinical
Research Branch, National Institute of
Diabetes and Digestive and Kidney Diseases
National Institutes of Health
Phoenix, AZ
USA

Emily Nangle

Department of Epidemiology, School of
Global Public Health
New York University
New York, NY
USA

Anna M. Nápoles

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Uchenna J. Ndulue

Boston Public Health Commission, Child
Adolescent and Family Health Bureau
Boston, MA
USA

Tung T. Nguyen

School of Medicine
University of California
San Francisco, CA
USA

Abigail Ortiz

Southern Jamaica Plain Health Center
Jamaica Plain, MA
USA

John E. Pachankis

School of Public Health
Yale University
New Haven, CT
USA

William V. Padula

Department of Pharmaceutical and Health
Economics, School of Pharmacy
University of Southern California
Los Angeles, CA
USA;
Leonard D. Schaeffer Center for Health
Policy and Economics
Los Angeles, CA
USA

Jane Pang

Pacific Islander Health Partnership
Huntington, Beach, CA
USA

Nina S. Parikh

Department of Epidemiology, School of
Global Public Health
New York University
New York, NY
USA

Eliseo J. Pérez-Stable

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Robert L. Phillips

American Board of Family Medicine
Washington, DC
USA

Latrice C. Pichon

Social and Behavioral Sciences
University of Memphis
Memphis, TN
USA

Tanjala S. Purnell

Johns Hopkins Center for Health Equity
Johns Hopkins University
Baltimore, MD
USA

Nishadi Rajapakse

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Amelie G. Ramirez

Institute for Health Promotion Research
University of Texas Health Science
Center
San Antonio, TX
USA

Neda Ratanawongsa

Division of General Internal Medicine,
Department of Medicine at Zuckerberg,
San Francisco General Hospital
University of California-San Francisco
San Francisco, CA
USA;
Center for Vulnerable Populations
University of California-San Francisco
San Francisco, CA
USA;
San Francisco Department of
Public Health
San Francisco, CA
USA;
Richard Fine People's Clinic
San Francisco, CA
USA

William T. Riley

Office of Behavioral and Social Sciences
Research
National Institutes of Health
Bethesda, MD
USA

Erik J. Rodriguez

National Heart, Lung, and Blood Institute
National Institutes of Health
Bethesda, MD
USA

Adelaida Rosario

Commissioned Corps Headquarters
Office of the Surgeon General
Rockville, MD
USA

Charles N. Rotimi

Center for Research on Genomics and
Global Health, National Human Genome
Research Institute
National Institutes of Health
Bethesda, MD
USA

Melanie D. Sabado-Liwag

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Mariana Sanchez

Robert Stempel College of Public Health
and Social Work
Florida International University
Miami, FL
USA

Milda R. Saunders

Department of Medicine
The University of Chicago
Chicago, IL
USA

Dean Schillinger

Division of General Internal Medicine,
Department of Medicine at Zuckerberg,
San Francisco General Hospital
University of California-San Francisco
San Francisco, CA
USA;
Center for Vulnerable Populations
University of California-San Francisco
San Francisco, CA
USA;
Richard Fine People's Clinic

San Francisco, CA
USA

Daniel Shriner

Center for Research on Genomics and
Global Health, National Human Genome
Research Institute
National Institutes of Health
Bethesda, MD
USA

Sarah C. Stallings

Vanderbilt University Medical Center
Nashville, TN
USA;
Meharry-Vanderbilt University
Nashville, TN
USA

Anita L. Stewart

Institute for Health and Aging, Center for
Aging in Diverse Communities
University of California
San Francisco, CA
USA

Andrea Williams Stubbs

St. Jude Children's Research Hospital
Memphis, TN
USA

Meryl Sufian

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Derrick C. Tabor

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA

Sora Park Tanjasiri

University of California
Irvine, CA
USA

Claudia Toledo-Corral

Department of Preventive Medicine, Keck
School of Medicine
University of Southern California
Los Angeles, CA
USA

Hannah A. Valentine

Scientific Workforce Diversity, Office of the
Director
National Institutes of Health
Bethesda, MD
USA

Elizabeth Vang

Department of Preventive Medicine, Keck
School of Medicine
University of Southern California
Los Angeles, CA
USA

Salina P. Waddy

Department of Neurology, Atlanta Veterans
Administration
Decatur, GA
USA

Nina Wallerstein

College of Population Health
University of New Mexico
Albuquerque, NM
USA

Joan Wasserman

Uniformed Services University of the
Health Sciences
Bethesda, MD
USA

Kristina Weeks

Johns Hopkins Center for Health Equity
Johns Hopkins University
Baltimore, MD
USA

Roy E. Weiss

Miller School of Medicine
University of Miami
Miami, FL
USA

Marquitta White

School of Medicine
University of California
San Francisco, CA
USA

Consuelo H. Wilkins

Vanderbilt University Medical Center
Nashville, TN
USA;
Meharry-Vanderbilt University
Nashville, TN
USA

Kesi Williams

National Institute on Minority Health and
Health Disparities
National Institutes of Health
Bethesda, MD
USA;
Center for Research to Advance
Community Health (REACH)
UT Health San Antonio
San Antonio, TX
USA

Jessamine Winer-Jones

IBM Watson Health
International Business Machines (IBM)
Corporation
Herndon, VA
USA

Cheryl A. Winkler

Frederick National Laboratory for Cancer
Research
National Cancer Institute
National Institutes of Health
Frederick, MD
USA

Kent Woo

NICOS Chinese Health Coalition
San Francisco, CA
USA

Shumei Yun

Resolve to Save Lives and Vital Strategies
New York, NY
USA

Xingyou Zhang

US Bureau of Labor Statistics
Washington, DC
USA

Xinzhong Zhang

Division of Clinical Innovation, National
Center for Advancing Translational
Sciences
National Institutes of Health
Bethesda, MD
USA

Foreword

January 10, 1992, the National Institutes of Health (NIH) published within its *Guide for Grants and Contracts*, special instructions to applicants regarding implementation of new policies concerning the inclusion of women and minorities in clinical research study populations. Many of the senior authors of chapters in this seminal volume and I were among those who advocated strongly for this, then, new policy. It spoke to the under-representation of racial and ethnic minorities in the science of the times, and strongly argued for closer attention to their inclusion in NIH-sponsored research as a means of improving said science. The introductory chapter to this volume chronicles the circumstances that led to this policy change, as well as the ensuing response on the part of the NIH and Department of Health and Human Services to its implementation.

Unfortunately, despite such a remarkable advance, the vigilance necessary to realize the promise embodied in this change waned. Indeed, as a long-standing member of several established NIH study sections charged with determining the scientific merit of thousands of grant applications submitted for prospective funding, I witnessed firsthand the gradual attenuation of this policy of inclusion. Study sections struggled with its operationalization; we lacked carefully crafted examples of how adherence to this policy could be accomplished in a pragmatic fashion and thus improve our science. As a consequence, reviewers gradually drifted from a rigorous application of the policy to a *pro forma* determination of the *adequacy* of including under-represented racial ethnic minorities, roughly equivalent to whether or not sampling plans assured their representation equal to that characteristic of the settings in which this work was to be conducted. One seldom read arguments, for example, for oversampling special populations in a manner that would truly test the hypotheses underpinning the proposed research, and thereby address race, ethnicity, or disadvantage as possibly important sources of variation in the phenomena under study.

Again, numerous contributors to this volume who also served on NIH study sections shared this concern and lamented the absence of careful attention to the implications for the science. Understanding the original arguments for why, *scientifically*, such individuals should be included in the work sponsored by NIH gradually faded; inattention diluted the promise of this remarkable policy. Arguments for the inclusion of under-represented racial and ethnic minorities and the disadvantaged in NIH-sponsored research eventually shifted from the benefit to science to the underlying importance of health equity and social justice. While the latter are important motives for undertaking such work, they are, in my opinion, necessary, but not sufficient conditions for promoting knowledge acquisition and ensuring the scientific merit of such efforts.

One and one-half decades later, the now National Academy of Medicine reviewed the NIH's strategic research plan to reduce and ultimately eliminate health disparities. This assessment essentially focused on the impact of the National Center on Minority Health and Health Disparities as of 2006, just prior to elevation to its current Institute status. In the Academy's report, the committee, of which several authors in this volume and I were members, concluded that the unfinished business of the Center and NIH was to revitalize a focus on the relevant science and to offer a coherent thematic framework for its pursuit. An emphasis on the social determinants of health emerged and gained increasing currency in anticipating and focusing this work. As the present volume amply demonstrates, this particular framework has played a critical role in organizing attention to the key domains and related constructs that bear importantly on the science underpinning minority health and health disparities research today.

This volume, and its companion piece in the special issue of the *American Journal of Public Health*, provide a roadmap to guide the science in this area. The chapters contained herein illustrate the importance and *feasibility* of systematic, rigorous inquiry for understanding the specifics of minority health and health disparities. They also convey the importance of the lessons learned for science in general: for discovery, for generalizability, for advancing theory, for enhancing measurement, for improving investigative methods, for promoting attention to neglected areas of research, and for diversifying the scientific work workforce. *The Science of Health Disparities Research* returns us to the spirit of 1992, and conviction, albeit now *empirically* demonstrable, that work of this nature can be exacting, meritorious, innovative, and broadly relevant. I applaud my colleagues' efforts in this regard and am confident those who follow can more effectively integrate health equity, social justice, and good science in service of improving the health of racial and ethnic minorities, as well as the disadvantaged, and humankind in general.

Spero M. Manson, PhD

Distinguished Professor of Public Health and Psychiatry
Colorado Trust Chair in American Indian Health
Colorado School of Public Health
University of Colorado Anschutz Medical Campus

Acknowledgements

We would like to thank all of the scientists, clinicians, and community-based researchers who have contributed to the scientific literature on minority health and health disparities research. Their vast contributions to the field serve as the foundation for this text. We also would like to thank chapter authors for their commitment to this project and their submissions. Further, we are eternally grateful to the staff of the National Institute on Minority Health and Health Disparities for their support, suggestions, and advice that helped us refine our ideas. Finally, we extend special thanks to Ligia Artiles and Richard C. Palmer for the immeasurable support they provided in successful completion of this project.

1

Definitions, Principles, and Concepts for Minority Health and Health Disparities Research

Eliseo J. Pérez-Stable¹, Jennifer Alvidrez¹, and Carl V. Hill²

¹National Institute on Minority Health and Health Disparities, National Institutes of Health, Bethesda, MD, USA

²Office of Special Populations, National Institute on Aging, National Institutes of Health, Bethesda, MD, USA

1.1 Introduction

In 1985, Department of Health and Human Services (DHHS) Secretary Margaret Heckler commissioned a report on minority health at the urging of African American health leaders. The Heckler Report on Black and minority health examined the health status of Americans by race/ethnicity and identified the gaps in disease rates, mortality, and other outcomes among Blacks compared to Whites [1]. The report provided a foundation for the scientific field of minority health research and legitimized a perspective that had been developing for several decades. At the time, the public health paradigm was to evaluate health differences in populations from a socioeconomic perspective and access to care on the assumption that these were the main drivers of health outcome differences. The Heckler Report introduced the notion at a national level that race and ethnicity may be an independent contributor to health outcomes, which merited scientific study and targeted intervention programs. In 1987, the DHHS Office of Minority Health was founded, led by Herb Nickens, MD.

In 1990, the Office of Minority Programs was founded at the National Institutes of Health (NIH) under DHHS Secretary Louis Sullivan, MD. In 1993 the name was changed to the Office of Minority Health Research. Through congressional legislation, this office was transformed in 2000 into the Center on Minority Health and Health Disparities, and in 2010 to the National Institute on Minority Health and Health Disparities (NIMHD). John Ruffin, PhD was the director from 1990 until his retirement in 2014.¹

In 1999, DHHS Deputy Secretary David Satcher, MD cited the unacceptability of demonstrated healthcare disparities by race in commenting on a study published in the *New England Journal of Medicine*, showing that Blacks were less likely to be referred for cardiac

1 <https://www.nimhd.nih.gov/about/overview/history/>

evaluation when presenting with classic chest pain symptoms compared to Whites [2]. Two years later, the Institute of Medicine (IOM) published the Unequal Care report summarizing a legacy of unequal healthcare and more adverse results for most leading causes of death and disability in the United States among African Americans compared to Whites [3]. Remarkably, little data were contained in this Report about the status of other race/ethnic groups in the United States. The IOM report broke down silos and provided the field with unifying principles about healthcare disparities. These events brought together scientific disciplines from population health, social science, and clinical care to focus on minority health and health disparities research.

In the twenty-first century, data collection and availability have dramatically improved. Scientific advances in understanding basic biological mechanisms have transformed our understanding of etiological pathways and potential interventions to improve minority health and reduce health disparities. The creation of a critical mass of interdisciplinary investigators has made possible further development of the science of minority health and health disparities. Collaboration among all health-related disciplines will make it possible for the next generation of minority health and health disparities researchers to advance the science. In that spirit, NIMHD is producing this book as it celebrates its tenth anniversary as an NIH Institute to further advance the science and lay the foundation for future research.

1.2 NIMHD Mission

NIMHD is charged with coordinating and leading the NIH's vision and programs on minority health and health disparities research by funding research to improve minority health and reduce health disparities. The topics are broad and include the epidemiology, etiology, prevention, and treatment for all diseases across the life course for all health disparity populations. Research that advances understanding and improvement of health and disease in minority racial/ethnic groups in the United States is a primary area of interest, requiring a basic understanding of race and ethnicity in the context of science. Research to understand the causes of health and healthcare disparities, leading to interventions to reduce these disparities, is NIMHD's mandate. The training and development of a diverse scientific workforce is also part of a broad NIH mandate embraced by NIMHD. NIMHD envisions an America in which all populations will have an equal opportunity to live long, healthy, and productive lives.

1.3 Definitions and Concepts of Minority Health and Health Disparities

1.3.1 Racial/Ethnic Minority Populations

In 1997, the Office of Management and Budget (OMB) issued the Revisions to the Standards for the Classification of Federal Data on Race and Ethnicity.² These standards are used for federal data collection purposes in the decennial US census, national household surveys,

2 <https://www.whitehouse.gov/wp-content/uploads/2017/11/Revisions-to-the-Standards-for-the-Classification-of-Federal-Data-on-Race-and-Ethnicity-October30-1997.pdf>

many administrative forms, and in medical and clinical research. Race and ethnicity categories have been modified over the decades to reflect the evolving demography of the United States, although full understanding of the meaning of the constructs captured by these categories is lacking and the categories need ongoing refinement and study. Currently, the five categories for race are defined as: American Indian or Alaska Native, Asian, Black or African American, Native Hawaiian and Other Pacific Islander, and White. In addition, a multirace category was included for the first time in the 2000 census. There are two categories for ethnicity: “Hispanic or Latino” and “Not Hispanic or Latino” and the question of ethnicity is posed before the race categories. The 2020 census plans to ask about family background for all respondents and continue to collect information on nation or US territory of origin for Hispanics/Latinos, Other Pacific Islanders and Asians, as well as tribal affiliation for American Indians/Alaska Natives. We consider that standardization of race and ethnic categories is an essential component of minority health and health disparities research and recommend using the census nomenclature and definitions as the starting point for specificity and standardization in the field.

1.3.2 Minority Health and Minority Health Research

NIMHD defines minority health research as the study of all aspects of health and disease in one or more OMB-defined racial/ethnic minority populations. Minority health research can include comparative research to examine and understand better or worse health outcomes in a racial/ethnic minority group relative to other groups. For example, greater prostate cancer mortality in African American men compared to White men, longer life expectancy in Asian and Hispanic/Latino populations compared to the general population, and higher rates of diabetes in all minority groups. Minority health research also encompasses within-group variation in health, such as asthma prevalence and morbidity in Puerto Ricans compared to Mexican Americans, and variation in cancer rates among American Indians from different regions. Minority health research can also address health conditions or risk and resilience factors specific to or disproportionately found in specific racial/ethnic minority groups, such as pain management in African American sickle cell patients and the use of native or traditional medicines or health practices by American Indians/Alaska Natives and other population groups.

An overarching common theme for all racial/ethnic minorities in the United States is to share a common experience of having been subject to some level of discrimination or social exclusion, which vary across groups and by socioeconomic status (SES) and need to be placed in historical and current contexts. The historical trauma experienced by American Indians as they were displaced from their lands and restricted to reservations, and the legacy of slavery for Black Americans carry a special burden. Moreover, societal discriminatory practices, like redlining to support residential segregation, have affected racial/ethnic minorities and are a fundamental cause that must be understood in order to reduce health disparities.

1.3.3 Health Disparities and Health Disparities Research

NIMHD defines a health disparity as a health difference, based on one or more health outcomes, that adversely affects defined disadvantaged populations. According to the legislation that created NIMHD, a health disparity population is characterized by a pattern of poorer

health outcomes, indicated by the overall rate of disease incidence, prevalence, morbidity, mortality, or survival in the population as compared to the health status of the general population. NIH-designated health disparity populations were defined in this legislation and the authority to modify these designations was given to the director of NIMHD in consultation with the director of the Agency for Healthcare Research and Quality (AHRQ). Currently designated health disparity populations include the racial/ethnic minority groups mentioned above, populations of less privileged SES or poor persons from any race/ethnic group, underserved rural populations, and sexual and gender minorities. Health disparities research is devoted to (i) understanding determinants that cause, sustain, or mitigate health disparities; and (ii) how this knowledge is translated into interventions to reduce disparities.

NIMHD's definition of health disparities emphasizes an adverse difference in populations with a social disadvantage. From the NIMHD perspective, a defined difference in health outcomes between populations is not necessarily a disparity. We define disparity as a difference between a disadvantaged population and a more advantaged referent population or the general population.

By comparison, in *Healthy People 2020*, the contributions of social determinants to an individual's ability to achieve good health also include sex, age, and disability.³ *Healthy People 2020* defines a health disparity as "a particular type of health difference that is closely linked with social, economic, and/or environmental disadvantage." The NIMHD definition emphasizes the disadvantage of population groups, and thus all adverse health outcomes within the designated population groups are considered health disparities. The NIMHD definitions also emphasize the importance of the historical or current link to discrimination or exclusion in determining health and healthcare disparities. The contributions of biological mechanisms, healthcare access and quality, and interventions to ameliorate disparities also need to be considered.

1.3.4 Is It Minority Health or Health Disparities?

There is substantial overlap in minority health research and health disparities research, in particular, research that focuses on worse health outcomes among particular racial/ethnic minority groups compared to Whites or other populations (Figure 1.1). For example, the

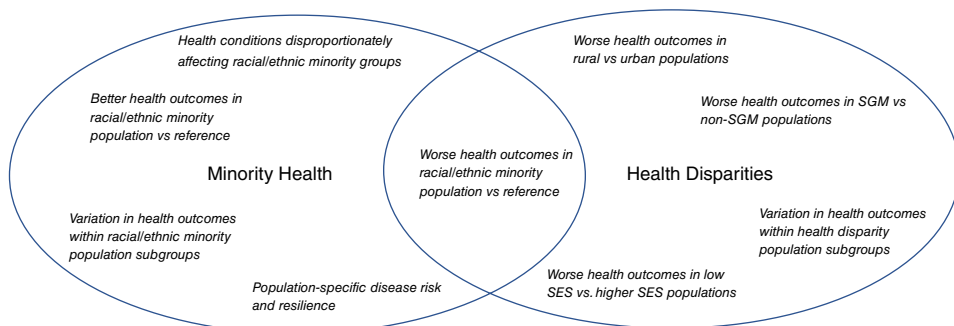


Figure 1.1 Overlapping but distinct constructs of Minority Health and Health Disparities Research.

3 <https://www.healthypeople.gov/2020/about/foundation-health-measures/Disparities>