NATIONAL ACADEMIES Sciences Engineering Medicine

Improving Public Health Data Systems to Address Health Equity Challenges for At-Risk Communities in the U.S. Gulf Coast

Workshop Materials

New Orleans, LA

May 16 - 17, 2023

NATIONAL ACADEMIES Sciences Engineering Medicine

GULF RESEARCH PROGRAM

Workshop: Improving Public Health Data Systems to Address Health Equity Challenges for At-Risk Communities in the U.S. Gulf Coast

May 16 - 17, 2023

Location:
New Orleans Marriott
555 Canal St.
New Orleans, LA 70130

Workshop Materials:

- Agenda
- Speaker Biographies
- Funding Opportunity: Improving Public Health Data Systems to Address Health Equity Challenges for At-Risk Communities in the U.S. Gulf Coast
- Public Health 3.0: A Call to Action for Public Health to Meet the Challenges of the 21st Century
- Charting a Course for an Equity-Centered Data System: Recommendations from the National Commission to Transform Public Health Data Systems

NATIONAL ACADEMIES *Sciences Engineering Medicine*

GULF RESEARCH PROGRAM

<u>Workshop</u>
Improving Public Health Data Systems to Address Health Equity Challenges for At-Risk Communities in the U.S. Gulf Coast

Agenda

May 16-17, 2023

New Orleans Marriott
555 Canal Street, New Orleans, LA 70130

<u>For those joining virtually:</u>

Zoom: https://nasem.zoom.us/j/91202330150?pwd=UjFnYVJSMkZscTRvQzk1ellFaGNFZz09
Meeting ID: 912 0233 0150
Password: 136715
Or call: 888 475 4499 (Toll Free)

Objectives

- Engage with diverse experts (e.g., panelists, other workshop attendees) while developing a proposal for the funding opportunity *Improving Publc Health Data Systems to Address Health Equity Challenges for At-Risk Communities in the US Gulf Coast*.
- Gain deeper understanding of key topics from the funding opportunity: community-based participatory research and community engagement, historical inequities and environmental health disparities, fundamental causes (i.e., social determinants of health), environmental and climate justice, equity-centered data, and translating data metrics into policy interventions.
- Increase networking opportunities among potential applicants.

	Tuesday May 16, 2023
7:00 – 9:00 AM	**REGISTRATION**
8:00 – 9:00 AM	**BREAKFAST**
9:00 – 9:05 AM	**Welcoming Remarks / Charge for The Day** **Dr. Charlene Milliken** Senior Program Manager, Gulf Research Program National Academies of Sciences, Engineering, and Medicine

9:05 – 9:20 AM	**Brief Introductions**
9:20 – 9:45 AM	**Overview of the GRP-RWJF partnership and Funding Opportunity** **Dr. Charlene Milliken** Senior Program Manager, Gulf Research Program National Academies of Sciences, Engineering, and Medicine **Dr. Francisca Flores** Program Officer, Gulf Research Program National Academies of Sciences, Engineering, and Medicine
9:45 – 11:00 AM	**PANEL: Viewing Health Disparities and their Fundamental Causes through the Community Perspective** – *Moderator:* **Dr. Catherine McKinley**, Associate Professor, Tulane University *Panelists* **Ms. Judith Smith** Health Director Port Arthur City Health Department | Port Arthur, TX **Mr. John Beard** Founder & Executive Director Port Arthur Community Action Network | West Port Arthur, TX **Mr. Sage Michael Pellet** New Orleans Climate Justice Organizer Healthy Gulf | New Orleans, LA **Ms. Jacquilyn R. German** Jackson Heart Study Mississippi State Department of Health | Jackson, MS
11:00 – 11:15 AM	**BREAK**
11:15 AM – 12:00 PM	**WORKSHOP: Viewing Health Disparities and their Fundamental Causes through the Community Perspective**
12:00 – 1:00 PM	**LUNCH**
1:00 – 2:00 PM	**PANEL: Uncovering the Fundamental Causes of Health Disparities --- A National Perspective on Social Determinants of Health Data** – *Moderator:* **Dr. Angela Heads**, Associate Professor, McGovern Medical School

Panelists

Ms. Carter Blakey
Deputy Director, Office of Disease Prevention and Health Promotion
U.S. Department of Health and Human Services | Washington, DC

Environmental Justice Index Team
Agency for Toxic Substances and Disease Registry
Centers for Disease Control and Prevention | Atlanta, GA

Dr. Matthew Tejada
Director, Office of Environmental Justice
Environmental Protection Agency | Washington, DC

2:00 – 2:30 PM **BREAK**

2:30 – 3:30 PM **PANEL: Bridging Clinical Determinants with the Fundamental Causes of Health Disparities – A Local Perspective on Social Determinants of Health Data**

- *Moderator:* **Dr. Lisa Patel**, Clinical Associate Professor of Pediatrics, Stanford School of Medicine, Executive Director, Medical Society Consortium on Climate and Health

Panelists

Ms. Lonias Gilmore
Director of Health Equity and Social Justice
Big Cities Health Coalition | Takoma Park, MD

Dr. Solange Gould
Co-Director
Human Impact Partners | Oakland, CA

Dr. AJ Scheitler
Director of Stakeholder Relations
Coordinator of the National Network of State and Local Health Surveys
UCLA Center for Health Policy Research
University of California Los Angeles | Los Angeles, CA

3:30 – 4:30 PM **WORKSHOP: Bridging Clinical Determinants with the Fundamental Causes of Health Disparities – Selecting Social Determinants of Health Data**

4:30 – 4:45 PM **WRAP UP & ADJOURN**

Dr. Charlene Milliken
Senior Program Manager, Gulf Research Program

National Academies of Sciences, Engineering, and Medicine

5:00 – 6:15 PM **Reception**

WEDNESDAY
MAY 17, 2023

8:00 – 9:00 AM **Networking Breakfast**

9:00 – 9:45 AM **PRESENTATION: Using Climate and Environmental Data to Advance Health Equity**

– *Moderator:* **Ms. Ivory Clarke,** Director, Culture of Health Program, National Academies of Sciences, Engineering, and Medicine

Presenters

Dr. Paul Juarez
Professor, School of Medicine, Health Disparities Research Center of Excellence, National Center for Medical Education Development & Research, Tennessee Area Health Education Centers Program
Meharry Medical College | Nashville, TX

Dr. Ibraheem Karaye
Assistant Professor of Population Health
Hofstra University | Hempstead, NY

9:45 – 10:45 AM **WORKSHOP: Using Climate and Environmental Data to Advance Health Equity**

10:45 – 11:00 AM **BREAK**

11:00 AM – 12:00 PM **PANEL: Using Data for Impact** (+Q&A)

- *Moderator:* **Dr. Mona Sarfaty,** Director, Program for Climate and Health, Center for Climate Change Communication, George Mason University

Panelists

Ms. Lindsey Cooper
Senior Gulf Coast Regional Policy Manager
Clean Air Task Force | Baton Rouge, LA

Mr. Lamar Gardere
Executive Director
The Data Center | New Orleans, LA

Ms. Kamaria Kaalund

	Policy Analyst Duke-Margolis Center for Health Equity | Durham, NC
12:00 PM – 1:00 PM	**WORKING LUNCH** **WORKSHOP: Using Data for Impact – How Data Can Better Inform Existing Health Agendas, Plans, Policies, Programs, Services, and/or Resource Allocation Methods**
1:00 – 1:30 PM	**BRINGING IT ALL TOGETHER: The Power of Data, Information, and Lived Experience in Frontline Communities** **Dr. Mark Mitchell** Associate Professor of Climate Change and Environmental Health Equity George Mason University | Fairfax, VA
1:30 PM	**WRAP UP & ADJOURN** **Dr. Charlene Milliken** Senior Program Manager, Gulf Research Program National Academies of Sciences, Engineering, and Medicine **Dr. Francisca Flores** Program Officer, Gulf Research Program National Academies of Sciences, Engineering, and Medicine

Workshop: Improving Public Health Data Systems to Address Health Equity Challenges for At-Risk Communities in the U.S. Gulf Coast

May 16 - 17, 2023

Speaker Biographies

PANEL: Viewing Health Disparities and their Fundamental Causes through the Community Perspective

Moderator:
DR. CATHERINE MCKINLEY
Associate Professor, School of Social Work
Tulane University

Dr. Catherine McKinley is an Associate Professor at the Tulane University School of Social Work after having attained her PhD in 2013 in social work from the University of Iowa. Dr. McKinley has worked with Indigenous tribes cross-nationally for over 10 years and works on federally funded community engaged research to develop and test culturally grounded interventions to promote family resilience and transcendence while addressing violence, substance abuse, and associated health disparities, including diabetes and health. Dr. McKinley serves as principal investigator of “Chukka Auchaffi’ Natana (In Choctaw): The Weaving Healthy Families Program to Promote Wellness and Resilience and Prevent Alcohol and Other Drug Abuse and Violence” with a supplement (3R01AA028201-01S1) focusing on the secondary health effects of COVID-19 promoting access, sustainability, and engagement with a digitally assisted intervention, through the use of SMS text messages. Her work may be found in 70 peer-reviewed publications and in collaboration with tribes led to the development of the Indigenous-based and ecological “Framework of Historical Oppression, Resilience, and Transcendence (FHORT)”, which identifies, and culturally relevant risk and protective factors related to wellness across community, family, and individual levels from a relational perspective.

Panelists:
JUDITH SMITH
Director of Health Services
Port Arthur City Health Department

Judith Smith is the Director of Health Services at the Port Arthur City Health Department. She oversees fourteen (14) divisions within the health department and provides public health services to South Jefferson County and surrounding cities. She started working for the City of Port Arthur in 1983 as staff nurse working in the Adult Health Services clinics. In 1993, she became the Nurse Supervisor for the TB (Tuberculosis) clinic under Texas Department of Health and worked this program for twelve years in the health department. Later in 2005, she became the Assistant Health Director and continued providing TB services to residents in the community who were impacted by TB disease and Latent TB infection.

Ms. Smith serves on the Boards for the Julie Rogers Gift of Life and the YMCA. She is a member of the Southeast Texas Black Nurses Association, the National Black Nurses Association and is a Rotarian. She is an ordained Minister and teaches Christian Doctrine at the Ruach School of Theology. Ms. Smith is the recipient of several awards including the "Save Our Children" Difference Maker award (2020-2021), Rotary "Presidential Award" (2021), Masonic Grand Lodge of Texas "Community Builder Award" for community service (2021) and the Arthur Stilwell Award for leadership during the COVID-19 pandemic. (2021) Ms. Smith has Bachelor of Science in Nursing and has been a Registered Nurse for the last 42 years.

JOHN BEARD

Founder & Executive Director
Port Arthur Community Action Network (PACAN)

John Beard, Jr. is the Founder and CEO of Port Arthur Community Action Network, an environmental, social justice and community development non-profit. After working in the oil industry for 38 years, Beard turned to holding the industry accountable and became a community advocate in his hometown. He founded the Port Arthur Community Action Network to fight for health and safety protections in an area teeming with refineries, export terminals, petrochemical plants…and cancer.

John's career in public service extends over 35 years three terms as a former city councilman and mayor protem, and he continues to serve on several city and state boards. He is active in the environmental justice movement, serving on the steering committees for the People vs Fossil Fuels, the Permian Gulf Coast Coalition, Break Free from Plastics, the Texas Hub of the Gulf South for a Green New Deal, Tap Root Earth and on the board of directors of Commission Shift Texas.

In the past year, Beard has emerged as an environmental justice leader on the national and world stage. John has been a delegate to the UN Climate Change conferences in Glasgow, Scotland and Sharm el-Sheikh, Egypt, in addition to the INC Plastics Conference in Punte del Este, Uruguay. He is a recipient of the 2021 Rose Bratz Award from the Center for Biological Diversity, and the Community Sentinel Award from the Halt the Harm Network.

SAGE MICHAEL PELLET

New Orleans Climate Justice Organizer
Healthy Gulf

As Healthy Gulf's New Orleans Climate Justice Organizer, Sage Michael is a local and established community activist and organizer working to better the quality of life in his hometown of New Orleans. Unfortunately, it is a city that faces constant disasters of flooding and loss of homes caused by climate change, an outdated stormwater system, and local citizens living with disaster trauma. His work is centered on community building with those underrepresented and most impacted and building coalitions to ensure community decision-making and a just transition in the process moving forward. His commitment and leadership are shown through his advocacy to restore and reopen historic Lincoln Beach.

JACQUILYN R. GERMAN

Community Partnership Director, Jackson Heart Study Community Engagement Center
Mississippi State Department of Health

Jacquilyn R. German currently serves as the Community Partnership Director for the Jackson Heart Study Community Engagement Center (CEC) at the Mississippi State Department of Health (MSDH). German's career experiences include administering population-based health promotion programs aimed at changing health behaviors through policy, environmental, and systems strategies. German's primary focus includes community-level chronic disease risk factor reduction, and mitigation of the social determinants of health that negatively impact where people live, work, worship, and play. Previously as the Community Health Bureau Director within the MSDH Office of Preventive Health and Health Equity, Ms. German oversaw programs in the Division of Injury and Violence Prevention, the State Employee Wellness Program, and the Impact of a Pre-School Obesity Prevention (IPOP) research study. In this position, she also provided functional supervision to Regional Community Health and Prevention Teams responsible for conducting statewide community-level activities for health promotion and disease prevention. German holds a Bachelor of Arts from Georgetown University in Washington, DC and Master of Public Health from Emory University, Rollins School of Public Health in Atlanta, GA.

PANEL: Uncovering the Fundamental Causes of Health Disparities --- A National Perspective on Social Determinants of Health Data

Moderator:

ANGELA HEADS
Associate Professor
McGovern Medical School, UTHealth Houston

Angela Heads, PhD, is a licensed psychologist with clinical expertise in evidence-based treatments for substance use disorders, anxiety and depression. She also has a specific interest in women's mental health issues. Heads' research interests include substance use and HIV prevention, psycho-cultural correlates of health risk, racial and gender related disparities in mental health and coping. She is currently working on a Substance Abuse and Mental Health Services Administration (SAMHSA) funded project studying substance use and HIV prevention in emerging adulthood.

Heads received her PhD in Counseling Psychology from Texas A&M University and completed a postdoctoral research fellowship in the Center for Neurobehavioral Research on Addiction (CNRA) at UTHealth. She joined the Department of Psychiatry and Behavioral Sciences as an assistant professor in 2015 to continue her research and clinical work with CNRA. She has also been actively involved in the training and clinical supervision of psychology doctoral students and psychology interns.

Panelists:

CARTER BLAKEY
Deputy Director, Office of Disease Prevention and Health Promotion
U.S. Department of Health and Human Services

Carter Blakey is the Deputy Director of the Office of Disease Prevention and Health Promotion (ODPHP) in the Office of the Assistant Secretary for Health (OASH) at the US Department of Health and Human Services (HHS). She also is the Director of ODPHP's Community Strategies Division (CSD). She has served in various roles across OASH, including Acting Chief of Staff, Acting Deputy Assistant Secretary for Health (Regional Operations), and Acting Regional Health Administrator. As the CSD Director, she provides leadership for various activities, including the Healthy People Initiative, a framework for public health priorities and actions comprised of a comprehensive set of ten-year national prevention objectives; and ODPHP's Healthy Aging and Social Determinants of Health portfolios.

Since the late 1990s, Ms. Blakey has worked on the myriad aspects of the Healthy People initiative, ranging from the development of the specific 10-year health objectives to implementation strategies across multiple sectors. Before joining ODPHP in 2001, her 13-year consulting career encompassed numerous activities in the health and biomedical arenas, including projects for the National Institutes of Health, the Congressional Office of Technology Assessment, the Council for Responsible Nutrition, the HHS Office of Public Health and Science, ODPHP, and CDC's National Center for Health Statistics. Previously, Ms. Blakey worked in public affairs and government relations for the Federation of American Societies for Experimental Biology; as a managing editor for FDC Reports, Inc., a publishing company specializing in health and the pharmaceutical industry; and as a teaching/research assistant at Georgetown University, Department of Biology.

MATTHEW TEJADA

Director, Office of Environmental Justice
Environmental Protection Agency

Matthew S. Tejada is the Deputy Assistant Administrator (DAA) for Environmental Justice within EPA's national program office for Environmental Justice and External Civil Rights (OEJECR). Matthew joined EPA in March of 2013 as a career senior executive and director of the Office of Environmental Justice (OEJ), a position he held until the reorganization of OEJ into OEJECR in September of 2022. As DAA, Matthew provides leadership for EPA's EJ portfolio, including the integration of EJ throughout all of EPA's policies, programs, and activities, coordination and alignment of EJ priorities with the external civil rights programmatic priorities, in addition to leading EJ efforts with other federal agencies, states, Tribes, local governments, and other stakeholders. Before his career at EPA, Matthew spent over five years as executive director of the environmental justice advocacy Air Alliance Houston in the Houston and Texas Gulf Coast area. Matthew received his master's and doctoral degrees from the University of Oxford where he was a member of St. Antony's College and a BA in English from the University of Texas at Austin, then served two years in the Peace Corps in Bulgaria. Matthew is a native of Ft. Worth, Texas, lives with his wife Andrea in Silver Spring, Maryland and is the proud father of Nia Tejada.

PANEL: Bridging Clinical Determinants with the Fundamental Causes of Health Disparities --- A Local Perspective on Social Determinants of Health Data

Moderator:

LISA PATEL

Clinical Associate Professor of Pediatrics, Stanford School of Medicine
Executive Director, Medical Society Consortium on Climate and Health

Dr. Lisa Patel is the Executive Director of the Medical Society Consortium on Climate and Health, and Clinical Assistant Professor of Pediatrics at Stanford School of Medicine. She is a former Presidential Management Fellow for the Environmental Protection Agency where she coordinated the US

Government's efforts on clean air and safe drinking water projects in South Asia in collaboration with the World Health Organization and received the Trudy A. Specinar Award for her work. She is a member of the Executive Committee for the American Academy of Pediatrics Council on Environmental Health and Climate Change and a faculty mentor for Stanford Climate and Health. As a mentor, she works with students and residents on projects related to climate-resilient schools, environmental justice, sustainable healthcare, and medical education curriculum reform. She maintains her clinical practice as a pediatric hospitalist caring for premature infants, attending deliveries, and caring for hospitalized children. Lisa received her Master's in Environmental Sciences from the Yale School of the Environment, her medical degree from the Johns Hopkins School of Medicine, and completed her training in pediatrics at UCSF.

Panelists:

LONIAS GILMORE
Director of Health Equity and Social Justice
Big Cities Health Coalition

Lonias Gilmore, MPH, is the Director of Health Equity and Social Justice for the Big Cities Health Coalition. BCHC is a forum for the leaders of America's largest metropolitan health departments to exchange strategies and jointly address issues to promote and protect the health and safety of the more than 61 million people they serve.

Lonias is a mission-driven public health practitioner who believes we can eliminate the power in race, culture, home language, zip code, and socioeconomic status to predict health and well-being. She has more than 10 years of experience building partnerships to improve public health and leading policy, systems, and environmental change to improve health and education outcomes and advance health and racial equity.

Prior to joining BCHC, Lonias was a senior public health consultant with the Michigan Department of Health and Human Services. Lonias was charged with protecting and promoting childhood nutrition and physical activity starting in the prenatal period through adolescence. She provided consultation and technical assistance nationally to government agencies, coalitions, workgroups, statewide partners, and community organizations on strategies to improve health and education outcomes and advance racial equity. She has also been involved in organizational change efforts to increase capacity to advance equity and to increase diversity and inclusion. Lonias received a master's degree in public health from the University of Oklahoma Health Sciences Center and a bachelor's degree in biology from Langston University, the Historically Black University in Oklahoma.

SOLANGE GOULD
Co-Director
Human Impact Partners

Dr. Solange Gould is Co-Director at Human Impact Partners. Along with Lili Farhang, she's responsible for advancing the mission and strategic direction of the organization. She has been in public health practice for over 20 years, advancing progressive policy and systems change to improve health, equity, and sustainability with government partners, advocates and organizers, and communities most impacted. Solange is excited about the clarity and vision of the youth climate movement in naming how racism, late-stage capitalism, and the climate crisis are intertwined root causes of inequities, and inspiring a vision of a future that everyone wants to run towards. Dr. Gould has a DrPH and MPH from University of California, Berkeley.

AJ SCHEITLER
Director, UCLA Center for Health Policy Research
University of California Los Angeles

AJ Scheitler, Ed.D., is the Development, Engagement and Strategic Planning at the UCLA Center for Health Policy Research. She leads the Center's development activities and fosters funder relationships. Scheitler also manages several large programs at the Center, including the Data Equity Center and the National Network of Health Surveys, a national collaboration of population health survey leaders and data users promoting the improved collection and dissemination of critical local and state health data. Additionally, she conducts research projects to provide evidence for policy making in areas of patient experience and intersections of health and education.

Prior to joining the Center, Scheitler conducted federal resource development activities for a number of institutions of higher education and lobbied Congress and the federal government for the interests of education organizations and post-secondary schools. She has experience at the state government level as well, having served as the Chief of Staff for the Florida Senate Minority Leader.

Scheitler holds a doctorate in higher education administration from Northeastern University, a master's degree in adult education and training from Colorado State University, and a bachelor's degree in communications from the University of Central Florida.

PANEL: Using Climate and Environmental Data to Advance Health Equity

Moderator:
IVORY CLARKE
Director, Culture of Health Program
National Academies of Sciences, Engineering, and Medicine

Ivory Clarke is a Senior Program Officer and the Equity and Inclusion Officer at the NAM. In her roles, she directs the NAM Culture of Health Program, a multiyear collaborative effort funded by the Robert Wood Johnson Foundation to identify strategies to create and sustain conditions that support equitable good health for everyone living in America. She is also responsible for developing and implementing an organizational strategy that operationalizes NAMs commitment to inclusion, diversity, equity, and anti-racism. Prior to these roles, Ivory has supported a range of projects within the Academies focusing on education, health and the environment. Ivory holds a master’s degree in Environmental Planning and Management from the Johns Hopkins University, Whiting School of Engineering and received her bachelor’s degree from the University of Chicago.

Presenters:
PAUL JUAREZ
Professor, School of Medicine, Health Disparities Research Center of Excellence, National Center for Medical Education Development & Research, Tennessee Area Health Education Centers Program
Meharry Medical College

Dr. Juarez is nationally recognized for his research in health disparities, particularly in the area of injury prevention, and for using community based participatory research methods. He was appointed in December 2016 as Chair, Advisory Committee on Minority Health, Office of Minority Health, and US Department of Health and Human Services. Dr. Juarez has been at the forefront nationally in using the exposome paradigm to identify the mechanisms and pathways through which environmental exposures 'get under the skin.' He has led a transdisciplinary team that has pioneered efforts that look at the effects of the natural, built, and social environments on health and health disparities at critical developmental periods across the lifespan and in applying "big data" computational methods and analytics to population health. Dr. Juarez has published widely on topics of the exposome, youth violence, health equity, and community engagement.

IBRAHEEM KARAYE

Assistant Professor of Population Health
Hofstra University

Dr. Karaye's impressive scholarship has been recognized nationally, including receiving a publication award from the American Journal of Preventive Medicine and being appointed to the National Academies of Sciences, Engineering, and Medicine's Committee to analyze how advanced environmental health and geospatial data can inform federal investments in communities of need. He is also an Academic Editor for PLOS ONE. Dr. Karaye holds a medical degree from Bayero University Kano, a Master of Public Health degree in epidemiology, and a doctorate in public health with a specialization in epidemiology and environmental health from Texas A&M University. At Hofstra University, he was recently recognized as the 2023 Faculty Mentor-of-the-Year.

PANEL: Using Data for Impact

Moderator:

MONA SARFATY

Executive Director Emeritus
Medical Society Consortium on Climate and Health

Dr. Mona Sarfaty is the Founder and Executive Director emeritus of the Medical Society Consortium on Climate and Health (Consortium). The Consortium is comprised of societies representing 70% of all U.S. physicians. Her research on physicians' experiences and attitudes about climate change, in conjunction with the George Mason University Center for Climate Change Communication, led to founding the Consortium in 2016. Dr. Sarfaty has been actively engaged in education, communication and policy development regarding the impact of climate change on health for over 15 years. She currently serves on a National Academy of Medicine Work Group on Decarbonization of the health system. She is the author of *Climate Change and Population Health: A Primer* (JB Learning, 2021), peer-reviewed articles, reports, and two book chapters on climate change and health, as well as widely circulated guides and peer reviewed articles on how to increase colorectal cancer screening rates.

Dr. Sarfaty is trained in family medicine and public health and has engaged in teaching, research, and advocacy for 40 years. She was Senior Health Policy Advisor for the U.S. Senate Health and Human Resources Committee (now H.E.L.P.) for 7 years. She developed and negotiated policy, and wrote legislation that established notable new programs, including The Emergency Medical Care and

Treatment of Labor Act (EMTALA), the Comprehensive HIV Information and Research Act, the Excellence in Minority Health Education and Care Act, the Geriatric Training Act, and the Foundation for the NIH, and the National Center for Rehabilitation Research.

Subsequently, she founded the Community Oriented Primary Care Track at the George Washington School of Public Health (now Milken Institute School), Project Access and the Primary Care Coalition of Montgomery County, MD, and the Diabetes Information and Support for Your Health group-visit program at Thomas Jefferson University. She also participated in the founding the Thomas Jefferson University School of Population Health. She served on the National Colorectal Cancer Roundtable for a decade. She did postdoctoral training at UCSF, received her MD from the State University of New York at Stony Brook, her MPH from George Washington University, and her BA from Harvard University.

Panelists:

LINDSAY COOPER
Senior Gulf Coast Regional Policy Manager
Clean Air Task Force

Lindsay Cooper joined the Clean Air Task Force in 2023 as Senior Gulf Coast Regional Manager for the U.S. State Policy team. Lindsay works across the Gulf South to develop and advocate for fact-based, nonpartisan, and equitable climate and clean energy policy. In this capacity, she partners closely with government officials, local communities, and other stakeholders to facilitate meaningful collaboration and innovative policy design for clean air and the net-zero economy.

Lindsay comes from the Office of Louisiana Governor John Bel Edwards where she managed Governor Edwards' Climate Initiative for three years. She established the Governor's Climate Initiatives Task Force and led development and implementation of Louisiana's first Climate Action Plan, the first state plan in the Gulf South designed to achieve net zero emissions by 2050. Lindsay spearheaded the most comprehensive state-level approach to decarbonization of the industrial sector to date, and she formed the Louisiana Interagency Grid Work Group to reduce barriers for clean energy deployment through effective programs and policies related to power grid securitization, modernization, and renewable integration.

In prior roles, Lindsay served as coastal resource advisor to Governor Edwards' Executive Assistant for Coastal Activities, advancing coastal insurability and flood risk management through interagency programs and congressional outreach. She previously worked as a coastal law research assistant for the Tulane Institute of Water Resources Law and Policy. Lindsay is a Louisiana native and a graduate of Tulane University.

LAMAR GARDERE
Executive Director
The Data Center

Lamar Gardere is the executive director of The Data Center and leads its mission to provide fully independent, objective, and reliable data for informed decision making in Southeast Louisiana. In his previous role as the City of New Orleans' Chief Information Officer, he was nationally recognized for his work developing the City's first ever data policy and the extensive data resources now available through the City's Open Data portal. Earlier years were spent as a researcher with the Georgia Institute of

Technology and with Intel Corporation's research division developing solutions for the challenges associated with an increasingly mobile, connected, and computationally rich society.

A New Orleans native, Lamar earned a Master of Science in Computer Science degree in ubiquitous computing from the Georgia Institute of Technology and a Bachelor of Science degree in computer science from Xavier University of Louisiana.

KAMARIA KAALUND

Policy Analyst
Duke-Margolis Center for Health Equity

Kamaria Kaalund is the Policy Analyst for Health Equity at Duke-Margolis. In this role, Kamaria supports health equity research projects, policy analysis, and educational initiatives. Her research interests include community-focused health policy approaches to reduce health inequities and the intersections between neuroscience, environmental health, and policy.

She is a 2020 graduate of Wellesley College where she earned a B.A. in Neuroscience and Anthropology. During her time at Wellesley, she worked with the: Early Childhood Cognition Lab at MIT on an online child development research platform; at the Computational Cognitive Development Lab at Rutgers University as a summer intern; and then within Wellesley's Centers for Women National SEED Project to support its goals of creating conversational communities that drive personal, organizational, and societal change toward greater equity and diversity.

BRINGING IT ALL TOGETHER: The Power of Data, Information, and Lived Experience in Frontline Communities

Speaker:

MARK MITCHELL

Associate Professor of Climate Change and Environmental Health Equity
George Mason University

Mark Mitchell M.D., MPH, FACPM is a senior member of the Center for Climate Change Communication's Program on Climate and Health team. A preventive medicine physician trained in environmental health and health policy, for over two decades Dr. Mitchell has worked in the public health sector -- including as Director of the Hartford, Connecticut Health Department -- and with environmental justice communities to prevent and reduce environmentally related disease and change policies that are detrimental to environmental health. Dr. Mitchell chairs the National Medical Association's Council on Medical Legislation and co-chairs the NMA's Commission on Environmental Health. He has also served on several U.S. EPA and FDA advisory committees and has received a number of awards for his community and environmental health leadership. Dr. Mitchell earned his medical degree from the University of Missouri-Kansas City and his Masters of Public Health from The Johns Hopkins University, and is the principal of Mitchell Environmental Health Associates, a consulting firm on environmental health and environmental justice issues.

Workshop Facilitators and Host Speakers

CARYN BELL

Assistant Professor
Tulane University

Caryn Bell's research focuses on the unique impacts of socioeconomic status (SES) and place on cardiovascular disease risk factors in Black Americans and racial disparities. Her work explores the nuanced ways in which SES is associated with obesity and related behaviors in Black women and men by examining the role of place and sociocultural factors. She uses varied techniques including spatial statistics and mapping approaches. She also examines how place shapes structural racism in the U.S. and the implications for Black health and racial health inequities. She teaches courses on health equity, racism and health, as well as, place and Black health in the U.S. Prior to joining the faculty at Tulane, she was an Assistant Professor of African American Studies at the University Maryland, College Park. She received her PhD in Social and Behavioral Sciences at the Johns Hopkins School of Public Health and a BS in Chemistry from the University of Maryland, Baltimore County.

ERICA SPEARS

Director of Monitoring, Evaluating, and Learning
Louisiana Public Health Institute

Erica Spears is a health equity leader with nearly 15 years of professional public health experience. She has worked in non-profit, governmental and academic spaces. Erica was recently hired as the Director of Monitoring, Evaluation and Learning (MEL) for Louisiana Public Health Institute. Erica holds a Bachelor of Arts degree in Mas Communication, with a major in Public Relations, from Louisiana State University. Her Master's degree is in Speech Communication, with an emphasis in Health Communication, from the University of Houston. Erica earned her Doctor of Philosophy degree in Health Education from Texas A&M University. She completed her Postdoctoral Research Fellowship at Auburn University's Center for Health Ecology and Equity Research. Erica has also been a selected research scholar for several health equity and health disparities training initiatives, including: the 9th cohort of the Health Equity Leadership Institute; the 2019 cohort of New Connections, sponsored by the Robert Wood Johnson Foundation; and the inaugural cohort of the Michigan Integrative Well-Being and Inequality (MIWI) Training Program.

CHARLENE MILLIKEN

Senior Program Manager, Gulf Research Program
National Academies of Sciences, Engineering, and Medicine

Charlene Milliken is a Senior Program Manager in the GRP's Health and Resilience Unit and leads the Enhancing Community Resilience (EnCoRe) Program that focuses on enhancing community efforts at the intersection of climate, health, and equity. Prior to the GRP, she managed programs and projects in the Policy & Global Affairs' Resilient America Program, partnering with communities to build community resilience to disasters. Before the National Academies, she spent seven years at the Department of Homeland Security Science and Technology Directorate working on projects related to community resilience, terrorism, technology transition, and social media use during disasters. Charlene was an AAAS National Defense and Global Security S&T Fellow (2007-2009) and a DHS Research Fellow (2009-2012). She has a B.A. in international relations from the University of Southern California and Ph.D. in anthropology from the University of Pittsburgh.

FRANCISCA FLORES
Program Officer, Gulf Research Program
National Academies of Sciences, Engineering, and Medicine

Francisca Flores is a Program Officer in the Gulf Research Program's Health and Resilience Unit, specifically working on the Enhancing Community Resilience Initiative. Prior to joining the GRP, she worked in PGA with the Resilient America Program, where she engaged diverse stakeholders from communities in Georgia, Maryland, Mississippi, Texas, and Virginia to explore aspects of community resilience to flood-related disasters in order to better understand risk perception, risk communication, and risk behaviors throughout the disaster cycle – before, during, and after flooding events. Before joining The Academies, Dr. Flores was a consultant for the World Health Organization (WHO) where she was involved in pioneering human security as a novel strategy for the public health efforts of WHO Member States in Central America and the Dominican Republic. Specifically, she focused on developing a methodology to enhance health and human security through the building of community resilience. Dr. Flores received her MPH and PhD degrees in behavioral and community health sciences and completed certificate programs in community-based participatory research and global health, from the University of Pittsburgh Graduate School of Public Health. Her dissertation research engaged a diverse group of stakeholders in exploring community resilience against gang violence and its harmful effects on adolescents, their families, and the community as a whole.

April 3, 2023

REQUEST FOR APPLICATIONS

Improving Public Health Data Systems to Address Health Equity Challenges for At-Risk Communities in the U.S. Gulf Coast

NATIONAL ACADEMIES
Sciences
Engineering
Medicine

GULF RESEARCH PROGRAM

Table of Contents

Summary of this Funding Opportunity

The Gulf Research Program (GRP) and Robert Wood Johnson Foundation (RWJF) are partnering to advance health equity[1] in at-risk[2] communities of the U.S. Gulf of Mexico that are disproportionately experiencing the impacts of climate change. This funding opportunity will support research to investigate the role that social determinants of health[3] (SDOHs) data could play in improving the capability of public health data systems to better understand and address health disparities[4] in at-risk communities (e.g., Black, Indigenous, and other People of Color [BIPOC] communities).

Specifically, the purpose of this funding opportunity is to support academic-community partnerships that use a community-based participatory research[5, 6] (CBPR) paradigm to demonstrate which data on climate-specific, environmental, and social determinants could better inform—and how these data could better inform—health agendas, plans, policies, programs, services, and/or resource allocation that address the health equity challenges of at-risk communities that are disproportionately experiencing the impacts of climate change.

The GRP is accepting proposals from accredited Minority Serving Institutions (MSIs) located in the five U.S. Gulf of Mexico states—Alabama, Florida, Louisiana, Mississippi, and Texas. Preference will be given to MSIs that partner with at-risk communities located in coastal regions along the Gulf of Mexico. One of the GRP's areas of interest is partnerships with environmental justice communities to better understand and address the impacts of climate change on environmental health disparities.[7]

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[1] *Health equity* is "the state in which everyone has the opportunity to attain full health potential and no one is disadvantaged from achieving this potential because of social position or any other socially defined circumstance." National Academies of Sciences, Engineering, and Medicine 2017. *Communities in Action: Pathways to Health Equity*. Washington, DC: The National Academies Press. https://doi.org/10.17226/24624.

[2] The GRP defines *at-risk* communities as those who are underserved, under-resourced, under-represented, or otherwise marginalized from the formal health sector.

[3] *Social determinants of health* are the "conditions in the environments in which people live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks. Some examples include education; employment; health systems and services; housing; income and wealth; the physical environment; public safety; the social environment; and transportation". National Academies of Sciences, Engineering, and Medicine 2017. *Communities in Action: Pathways to Health Equity*. Washington, DC: The National Academies. Press. https://doi.org/10.17226/24624.

[4] *Health disparities are* "preventable differences in the burden of disease, injury, violence or in opportunities to achieve optimal health experienced by socially disadvantaged racial, ethnic, and other population groups and communities". Centers for Disease Control and Prevention. (2021). Health Disparities. Retrieved on November 15, 2021 from https://www.cdc.gov/aging/disparities/index.htm.

[5] Israel B, Schulz A, Parker E, & Becker A. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Review of Public Health, 19*(1), 173–194.

[6] Wallerstein, N & Duran, B. (2006). Using community-based participatory research to address health disparities. *Health Promotion Practice, 7*(3), 312-323.

[7] *Environmental health disparities* exist when "communities exposed to a combination of poor environmental quality and social inequities have more sickness and disease than wealthier, less polluted communities". National Institute of Environmental Health Sciences. (2021). Environmental Health Disparities and Environmental Justice. Retrieved on December 2, 2021 from https://www.niehs.nih.gov/research/supported/translational/justice/index.cfm

Award Details

Total Amount Available	Up to $6,000,000
Award per Grantee	Up to $1,500,000
Period of Performance	23 months
Estimated Number of Awards	4

Key Dates

- **April 3, 2023:** Online proposal submission opens
- **June 12, 2023:** Deadline for submission of proposals due by 5:00 p.m. Eastern Time
- **June-September 2023:** Proposal review, and award selection and notification
- **October 1, 2023:** Project start date
- **August 31, 2025:** Project end date
- **October 31, 2025**: Final project reports due

Online submission website: https://gulfresearchprogram.smapply.io/.

The Challenge

In the U.S. Gulf of Mexico region, historic and deep racial discrimination has limited the meaningful involvement of BIPOC communities in the systems and institutions that make decisions about and implement the laws, regulations, policies, and practices that affect their communities.[8] This limitation has contributed to an inequitable concentration of poor environmental factors (e.g., air pollution, water contamination, toxins in the soil, etc.) and health outcomes in BIPOC communities that are well-documented in the scientific literature.[9] While climate change is projected to amplify the effects of poor environmental factors on health for all communities in the U.S. Gulf of Mexico, BIPOC communities will continue to be disproportionately impacted.

Advancing health equity involves looking critically at the conditions and environments that deny people the opportunity to achieve their full health potential. Specific conditions, known as SDOHs, shape the environments of everyday life that influence the health and well-being of communities. Differences in SDOHs account for 80-90 percent of the modifiable contributors of health behaviors, risks, outcomes, and patterns for a population.[10] Yet, existing public health data systems rarely collect data on SDOHs and commonly focus on clinical determinants of health (e.g., weight, blood pressure, cholesterol level,

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[8] Brulle, RJ, & Pellow, DN. (2006). Environmental Justice: Human Health and Environmental Inequalities. *Annual Review of Public Health, 27*, 103-24.

[9] Lave & Seskin (1970); Freeman (1972); Burch (1976); Melosi (1981); United Church of Christ (1987); Robinson (1991); Brown & Mikkelsen (1990); Brown (1992); Bryant & Mohai (1992); Mohai & Bryant (1992); Bullard (1990, 1993); Bullard & Wright (1993); Been (1994); Brulle & Pellow (2006); Leung & Takeuchi (2011); Centers for Disease Control and Prevention (2013)

[10] Hood, CM, Gennuso, KP, Swain, R, and Catlin, BB. (2016). County health rankings: Relationships between determinant factors and health outcomes. American Journal of Preventative Medicine, 50(2), 129 – 135.

etc.). Additionally, existing systems lack key demographic, climate-specific, and environmental factors that drive health disparities, as well as geospatial data at a more granular unit of analysis. Moreover, existing public health data systems operate within the formal health sector (e.g., clinics and hospitals, public health departments, health insurance companies, etc.) rather than within the community setting.[11]

Since the contributing factors (i.e., SDOHs, environmental quality, climate) that influence health in the places where people are born, grow, play, learn, work, live, worship, and age (i.e., the community setting) are often excluded from existing public health data systems, there is an incomplete representation of the burden and distribution of disease, disability, injury, and violence at the population level. As a result, existing public health data systems are not well-suited to understand the drivers behind persistent health disparities in at-risk communities, which may lead to inadequately-informed health agendas, plans, policies, programs, services, and/or resource allocation that fail to reach certain communities or even entire populations.[12] This failure leaves out-of-reach communities and populations underserved, under-resourced, under-represented, and/or marginalized by the formal health sector; overtime, these circumstances eventually give rise to health disparities (e.g., preventable differences in life expectancy, cardiovascular disease, etc.).[13]

Addressing health equity challenges requires a transformation in public health data systems and a shift in who/for whom, which, where, and how health equity data are identified, collected, analyzed, utilized, monitored, evaluated, and communicated.[14]

Purpose of this Funding Opportunity

The purpose of this funding opportunity is to support MSI-community partnerships that use a CBPR paradigm to demonstrate which SDOHs data, as well as data on climate-specific and environmental factors, could better inform—and how these data could better inform—health agendas, plans, policies, programs, services, and/or resource allocation that address the health equity challenges of at-risk communities that are disproportionately experiencing the impacts of climate change.

The GRP is accepting proposals from accredited MSIs located in one of the five U.S. Gulf of Mexico states: Alabama, Florida, Louisiana, Mississippi, and Texas. The GRP expects to award grants for 23-month projects that partner with an at-risk community and implement a project that balances the needs and priorities of all partners.

The GRP will provide opportunities for the MSI-community partnerships to further build relationships

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[11] McDavid Harrison, K., & Dean, HD. (2011). Use of data systems to address social determinants of health: A need to do more. Public Health Reports, 126(Suppl 3), 1 – 5.

[12] Venzon, A., Bich Le, T., & Kim, K. (2019). Capturing social health data in electronic systems: A systematic review. Computer, Informatics, Nursing: CIN, 37(2), 90 – 98.

[13] Centers for Disease Control and Prevention. (2013). CDC health disparities and inequalities report – United States. Mortality and Morbidity Weekly Report, 62(Suppl 3), 1 – 187.

[14] Salemi, JL, Salinas-Miranda, AA, Wilson, RE, & Salihu, HM. (2015). Transformative use of an improved all-payer hospital discharge data infrastructure for community-based participatory research: A sustainability pathway. Health Services Research, Suppl 1(Suppl 1), 1322 – 1338.

and engage networks through convening events (e.g., workshops, peer-to-peer learning activities, annual meetings, etc.).

MSI-community partnerships are encouraged to build diverse teams that include a variety of community stakeholders (e.g., nonprofit organizations, government, academia, private sector, etc.), including representatives and trusted leaders from at-risk communities. The GRP also encourages the inclusion of graduate students on project teams.

Funding Opportunity Guidelines

Requirements

To be responsive to this funding opportunity, the proposal must:

- incorporate the principles of CBPR[15, 16];
- work in and partner with an at-risk community;
- identify one or more major health disparity/disparities that affect the at-risk community and will be the focus of the partnership;
- identify (1) potential SDOHs of the selected health disparity/disparities to investigate and (2) possible data corresponding to those SDOHs (e.g., geospatial, demographic, climate-specific, and environmental factors); and
- identify how the data could advance health equity by improving the capability of existing public health data systems to understand and address health disparities; for example, how could the data inform a health agenda, plan, policy, program, service, and/or resource allocation to better addresses the health equity challenges of at-risk communities.

Eligibility

The GRP welcomes proposals from U.S. academic institutions that are accredited by the U.S. Department of Education as an MSI per the Higher Education Act of 1965. The applying organization will be referred to as the "applicant" hereafter. The individual who will lead the proposed project will be referred to as the "project director" hereafter.

<u>The GRP requires applicants to adhere to the following:</u>

- This funding opportunity is for new, distinct activities only. Proposed activities that augment a broader, existing effort or project may be eligible if the proposal clearly demonstrates that the funding request is for new, distinct activities that would not otherwise occur.
- Proposed activities involving advocacy or lobbying are not eligible.
- All applicants must have a valid U.S. federal tax ID number.
- U.S. federal agencies are not eligible to receive GRP funding as applicants or sub-awardees, although their employees may be non-funded collaborators.
- Federally Funded Research and Development Centers (FFRDCs) and University Affiliated Research Centers (UCARCs) can be named as sub-awardees, however, they must have the

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[15] Minkler, M. & Wallerstein, N. (2008) Community based participatory research for health: Process to outcomes. 2nd Edition, Jossey Bass: San Francisco.

[16] Burke, JG et al. (2013). Translating community-based participatory research principles into practice. *Progress in Community Health Partnerships: Research, Education, and Action, 7*(2), 115-122.

authority to obtain funding for work outside of their federal sponsor contact and not be proposing to do work they are otherwise doing under their federal sponsor contract.

- BP Exploration and Production, Inc. (BP), Transocean Deepwater, Inc. (Transocean), their affiliates, and employees are not eligible to receive grant funding or to participate in any grant.

The GRP requires the project director and key personnel in an application to adhere to the following:

- An individual may be named as Project Director in only one application.
- An individual, including a Project Director, may be named as Project Team Members in any number of other applications.
- If an individual appears on multiple proposals, a clear description should be included to explain how the proposed work is complementary and not duplicative of other proposed efforts and how the participant will budget his or her time.
- Should an individual appear on two or more proposals as Project Director, ALL proposals listing that individual as Project Director will be disqualified and eliminated from the review process. It is the responsibility of the Project Directors to confirm that each member of the entire team is within the eligibility guidelines.

Application Submission and Review

Please review the application preparation and submission instructions and submit any questions to gulfgrants@nas.edu prior to the submission deadlines. The GRP strives to respond to applicants' questions within two business days but cannot guarantee that applicants' questions will be answered before submission deadlines.

The GRP will only accept proposals submitted via the online application system. Full proposal materials submitted in any language other than English will not be considered. The GRP may reject, without review, proposals that are not responsive to the Request for Proposal instructions.

The applying institution or organization will be referred to as the "applicant" hereafter. The individuals who will lead the proposed project will be referred to as the "project directors" hereafter.

Project Proposal

The proposal must include the following elements:

I. **Applicant** (up to 500 words)
Describe the applicant, including their location; mission and/or vision statement; and research and/or practical experience with at-risk communities, CBPR, SDOHs, climate-specific and/or environmental factors, health disparities, and/or health equity.

II. **Project Team**
Project directors are encouraged to assemble diverse project teams. Partnerships with nonprofits, community-based organizations, and/or faith-based organizations that are representative of the at-risk community are highly encouraged.
    a. Project director. List the project director's name, email, organizational affiliation, type of institution, and project role.
        i. ORCID (Open Research and Contributor ID)

   b. Project team members. List the name, email, organizational affiliation, type of institution, and project role of each project team member in the order of their importance.
   c. Involvement of the project directors and project team members in other proposals related to this funding opportunity.

III. **Proposal Details**
   a. Proposal title (up to 15 words)
   b. Proposal key words (up to 10 words)
   c. Proposal summary (up to 250 words)
   d. Proposal timeline of activities (up to 1000 words). Alternatively, applicants may upload a Gantt chart or other type of project schedule.
   e. Project description and approach (7000 words)
      i. Background. Describe the project location; at-risk community of interest (e.g., demographics, history of being disproportionately impacted by climate change, rationale for selecting at-risk community); health disparities being investigated, related SDOHs, and corresponding data (e.g., geospatial, demographic, climate-specific, and environmental factors); relevant data sources and systems (e.g., what data are currently being collected on or related to the health disparities of interest, climate, or environmental factors and how?); and gaps and/or limitations in data, data sources, and data systems' capabilities.
      ii. Purpose and aims. Discuss: 1) what this project intends to accomplish, including which data gaps the project aims to fill, and 2) how the data selected for the project might better inform a health agenda, plan, policy, program, service, and/or resource allocation that benefits the health equity challenges of the at-risk community of interest.
      iii. Methodology. Describe: 1) the project design; 2) what CBPR principles will be incorporated into the project and how; 3) any framework(s) and/or approaches that will guide the project; 4) what methods you will use to collect, if applicable; 5) how you will use data to measure SDOHs, climate and environmental factors; and 6) how you will analyze the data.
      iv. Project assessment. Describe what success would look like for your project and how it will be measured.
      v. Potential for impact. Describe how the outcomes of this project could be useful to other communities and how the results of this project could change existing public health data systems.
   f. Works cited. Please provide a list of all works cited in the proposal.
   g. Data Management Plan (maximum 1500 words). Please refer to GRP's Data Management Policy for guidance on the development of the project Data Management Plan.
   h. If the proposed project involves research on human subjects or the use of human-subject data, see "Research Involving Human Subjects" below.

IV. **Required Attachments**
   a. **Proposal Budget Form** (template). Complete this form to provide information on the proposed budget. Budget requests should be developed commensurate with the support needed to achieve the project goals.
   b. **Budget Justification** (maximum 2,000 words). View a sample budget justification.

c. **Resume(s)**: A resume is required for the project director and each individual identified as a project team member. Resumes are limited to two pages for each person. Please combine all resumes into a single PDF document before uploading as an attachment. If a resume is longer than two pages, only the first two pages will be considered in peer review.

d. **Collaborators and Other Affiliations Form:** The purpose of this form is to help the GRP and RWJF eliminate potential conflicts of interest during reviewer recruitment. Download the form and complete it to provide information on the following:

   i. All persons (including their current organizational affiliations) who are currently, or who have been collaborators (i.e. an individual with whom you work closely to co-design or conduct a project) or co-authors with the individual on a project, book, article, report, abstract, or paper during the 48 months preceding the submission of the application.

   ii. The individual's own graduate and postdoctoral advisor(s) and their current organizational affiliations.

   iii. A list of your past and current advisees (including their current organizational affiliations)

e. **Current and Pending Support from Other Sources Form:** Download the form and complete it to provide information on current and pending support from other sources for the project director and key personnel, if applicable, and upload it to the online application system. The form requests information on the project director's and key personnel's current and pending support from other sources (e.g., ongoing projects and proposals). All current project support from whatever source (e.g., federal, state, local or foreign government agencies, public or private foundations, industrial or other commercial organizations) must be listed. The project proposed for this funding opportunity and all other projects or activities that require a portion of time of the project personnel and other senior personnel must be included, even if they receive no salary support from the project(s). The total award amount for the entire award period covered (including indirect costs) must be shown as well as the number of person-months per year to be devoted to the project, regardless of source of support.

V. Optional Attachments

   a. Letters of Support

Peer Review Process

Only complete applications meeting the eligibility criteria will be evaluated by external reviewers based on the Merit Review Criteria (see below). Funding decisions will take into consideration the reviewer's evaluations and the program's funding availability, current portfolio, objectives, and goals. The final decision for funding will be made by the National Academies. Visit our website to see the GRP's conflict of interest and confidentiality policies.

Merit Review Criteria for the Proposal

Proposals will be evaluated on the basis of four review criteria. The bullets under each criterion should guide applicants in writing their proposals and guide reviewers in evaluating a plan.

Relevance & Potential Impact (20%)

- To what extent does the proposal address the challenge?

- To what extent does the proposal describe how the identified SDOHs and corresponding data (e.g., geospatial, demographic, climate-specific, and environmental factors) could better inform a health agenda, plan, policy, program, service, and/or resource allocation to benefit the health equity challenges of the at-risk community?
- To what extent does the proposal describe how its outcomes could be useful to other communities?
- To what extent does the proposal describe how its results could change existing public health data systems?

Scientific Rigor (50%)

- To what extent does the proposal provide a well-justified rationale for selecting the at-risk community of interest?
- To what extent does the proposal describe how the identified SDOHs are relevant to the health disparity/disparities?
- To what extent do the identified geospatial, demographic, climate-specific, and/or environmental data correspond to the SDOHs?
- To what extent does the proposal incorporate the principles of CBPR?
- To what extent are the methods and data collection (if applicable) appropriate?
- To what extent are the data analysis/analyses and measurement appropriate?

Project Team (20%)

- To what extent is the project director well-qualified in their experience, knowledge, and skills to lead the proposed project?
- To what extent are the project team members well-qualified in their experience, knowledge, and skills to ensure the completion of a successful proposed project?

Feasibility and Budget (10%)

- To what extent is the proposal feasible within the 23-month period ?
- To what extent is the budget (up to $1,500,000) commensurate with the proposal?

Data Management Policy

The GRP's Data Management Policy will apply to this funding opportunity and should be considered in the planning process. To facilitate sharing of data and information products, all applications submitted to the GRP must include a data management plan and follow FAIR guiding principles (FAIR stands for "Findable, Accessible, Interoperable, Reusable." To learn more about FAIR guiding principles refer to the National Academies report *"Open Science by Design: Realizing a Vision for 21st Century Research"*).

The GRP follows the federal government's definition of data in the Office of Management and Budget (OMB) 2 Code of Federal Regulations (CFR) Section 200.315: "...the recorded factual material commonly accepted in the scientific community as necessary to validate research findings." Information products may include documents (i.e., reports, workshop summaries, etc.), multi-media curricula for education and training (i.e., video and/or online tutorials, manuals and handbooks, etc.), and other media and communication platforms. Even in the unlikely case in which no data or any other information products will be produced, a plan must be submitted that states "No data or information products are expected to be produced from this project."

The GRP's Data Management Policy and Data Management web page provide information on what must be included in the data management plan submitted as part of an application.

Research Involving Human Subjects Policy

The GRP's Research Involving Human Subjects Policy will apply to this funding opportunity and should be considered in the planning process. All projects involving human subjects must be submitted to an institutional review board (IRB) for review and either receive IRB approval or be granted exemption from human subjects' regulations before an award can be made. Proposers should file their application with their local IRB at the same time the application is submitted to the GRP so that any approval procedure determined as necessary will not delay the award process. An application may be submitted to the GRP prior to receiving IRB approval or being granted exemption; however, if the application is selected for funding, the award will be made conditional upon IRB granting approval or exemption from human subjects' regulations within 60 days of the notice of conditional award. If a proposed project involving human subjects is granted exemption from human subjects' regulations [see 45 CFR 46.101(b)], the Applicant must provide documentation that an IRB (or the appropriate authority other than the Project Director or Key Personnel) has declared the project exempt from the human subjects regulations. Documentation should include the specific category justifying the exemption. Organizations without internal access to an IRB must seek approval or exemption from an independent review board or other appropriate authority.

Making the Award

Selection Notice

The GRP reserves the right to select all, some, one, or none of the proposals received in response to this solicitation.

When the evaluation of a proposal is complete, the project director will be notified that (1) the proposal has been selected for funding pending contract negotiations, or (2) the proposal has not been selected. These official notifications will be sent via email to the project director identified on the application. If a proposal is selected for award, the GRP reserves the right to request additional or clarifying information for any reason deemed necessary, including, but not limited to, indirect cost information or other budget information. Awardees are free to accept or reject the grant agreement as offered.

Award Notice

The GRP transmits award notices to organizations via e-mail. The award is not finalized and the National Academies of Sciences, Engineering, and Medicine is not obligated to provide any funding until a signed copy of the award agreement has been received by the Academies.

Grant Periods

Upon receipt of the award notice, the awardee should note the effective date and the expiration date. Effective date is the date specified in the grant notice on or after which expenditures may be charged to the grant. Charging expenditures to the grant prior to the effective date is prohibited. Expiration date is the date specified in the grant notice after which expenditures may not be charged against the grant except to satisfy obligations to pay allowable project costs committed on or before that date. Once an award is made, the effective date cannot be changed. The expiration date may be changed as a result of approval of a request for a no-cost extension. If approved, the GRP will issue an amendment to the grant.

If additional time beyond the performance period and the established expiration date is required to assure adequate completion of the original scope of work within the funds already made available, the awardee may apply for a one-time, no-cost extension of up to six months. A formal request must be submitted to the GRP at least 45 days prior to the expiration date of the grant. The request must explain the need for the extension and include an estimate of the unobligated funds remaining and a plan for their use. This one-time extension will not be approved solely for the purpose of using the unliquidated balances.

Post-Award Management

Coordination with GRP

After the award is conferred, grantees shall coordinate with GRP to formally initiate the project. GRP staff will periodically request status meetings during the project to discuss progress and any unanticipated developments that may affect the project outcomes as specified in the grant agreement. These interactions will help ensure successful management of the grant.

Reporting Requirements

After an award is conferred, the grantee shall provide a semi-annual financial report to the GRP to report on grant expenditures to date under the grant. The grantee shall provide an annual written report to the GRP to report on activities being carried out under the grant, including but not limited to project accomplishments to date and grant expenditures. No later than sixty (60) days after the expiration of the award, the grantee shall provide in writing a final grant report. The final grant report shall address the original objectives of the project as identified in the grant proposal, describe any changes in objectives, describe the final project accomplishments, and include a final project accounting of all grant funds.

Data Management

Implementation of a data management plan will be monitored through the annual and final report process. Even when no data or any other information products will be produced, a plan must be submitted that states "No data or information products are expected to be produced from this project." Please see the GRP's Data Management Policy and Data Management web page for information on this requirement.

Scientific Integrity

A fundamental purpose of the GRP is to facilitate the advancement of knowledge and the application of science to address challenges relevant to the Program's mission. All activities of the GRP will be conducted to meet the highest standards of scientific integrity. All grantees have a responsibility to use the funds wisely.

Post-Award Evaluation

The Gulf Research Program conducts evaluations of its grantmaking in support of improving its practices and decision-making. These evaluations are intended to:

- Help build an evidence base that both grantees and the GRP can use to understand their impact.
- Enable organizational learning and increase capacity to provide quality programming.
- Support the sharing of successes, challenges, and insights among funders, grantees, and stakeholders.

The Gulf Research Program will monitor and evaluate the grant at reasonable times and at our expense, which may include visits by our representatives to observe your program procedures and operations, data collection by an evaluator, and/or discussion of the project with your personnel and stakeholders.

Grant Terms and Conditions

Please review the Grant Agreement prior to submitting an application. It is the policy of National Academies of Sciences, Engineering, and Medicine to entertain potential modifications to the Grant Agreement only under the most exceptional circumstances. Rather, successful applicants are strongly encouraged to sign the Grant Agreement as presented.

- View a sample grant agreement if the applicant is a public institution.
- View a sample agreement if the applicant is a private institution.

About the Gulf Research Program

The GRP is a division of the National Academies of Sciences, Engineering, and Medicine—a private, nonprofit organization with a 150-year history as an independent advisor to the Nation on issues of science, engineering, and medicine. The GRP was founded in 2013 as part of legal settlements with the companies involved in the 2010 Deepwater Horizon disaster, and received an endowment to carry out studies, projects, and other activities in the areas of research and development, education and training, and monitoring and synthesis.

The GRP seeks to enhance offshore energy safety, environmental protection and stewardship, and human health and community resilience in the Gulf of Mexico and beyond. It focuses its work on the Gulf of Mexico and other outer continental shelves of the United States where there is hydrocarbon production, and on their coastal zones; specifically, this includes the areas of the Southcentral region of Alaska that are or could be affected by activities (e.g., drilling, production, and transportation) associated with hydrocarbon production in the offshore. Where appropriate, the GRP's work may extend farther inland or into adjacent seas.

The GRP uses four strategic approaches to "catalyze, implement, and track positive impact in the Gulf of Mexico and beyond"[17]:

1. Advance science and understanding
2. Bridge knowledge to action
3. Build partnerships and engage networks
4. Monitor for progress and change

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[17] National Academies of Sciences, Engineering, and Medicine. 2020. *Gulf Research Program: 2020-2024 Strategic Plan*, pp. 3-4. Available at https://www.nationalacademies.org/_cache_0f9e/content/4885770000227383.pdf. Retrieved April 24, 2021.

The GRP's Health and Resilience Program

The Gulf Health and Community Resilience Program manages two major efforts: 1) the Gulf Health and Resilience Board which funds research and supports projects that develop approaches and solutions that advance science and understanding in health and community resilience, and 2) the Enhancing Community Resilience Initiative, a concerted community engagement program that applies science in select communities to support local health and community resilience efforts.

The overarching goal of the Health and Resilience Program is to advance equity in health and climate resilience efforts in the GRP's geographic areas of focus (i.e., the coastal areas of the Gulf region and Southcentral Alaska) by:

- Reducing inequities in health and community resilience.
- Advancing research and practice in health and community resilience.
- Building the capacity of communities to: 1) address the impacts of climate change and disasters on at-risk communities, and 2) sustain their disaster and climate resilience efforts.

The Health and Resilience Program uses two complementary frameworks to approach its work:

1. the SDOHs
2. the six community capitals[18]

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[18] National Academies of Sciences, Engineering, and Medicine. 2019. *Building and Measuring Community Resilience: Actions for Communities and the Gulf Research Program*, pp. 15-17. Washington, DC: The National Academies Press. https://doi.org/10.17226/25383.

Centers for Disease Control and Prevention

Preventing Chronic Disease

PREVENTING CHRONIC DISEASE
PUBLIC HEALTH RESEARCH, PRACTICE, AND POLICY

Public Health 3.0: A Call to Action for Public Health to Meet the Challenges of the 21st Century

SPECIAL TOPIC — Volume 14 — September 7, 2017 Am score 116

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Top

Abstract

Public health is what we do together as a society to ensure the conditions in which everyone can be healthy. Although many sectors play key roles, governmental public health is an essential component. Recent stressors on public health are driving many local governments to pioneer a new Public Health 3.0 model in which leaders serve as Chief Health Strategists, partnering across multiple sectors and leveraging data and resources to address social, environmental, and economic conditions that affect health and health equity. In 2016, the US Department of Health and Human Services launched the Public Health 3.0 initiative and hosted listening sessions across the country. Local leaders and community members shared successes and provided insight on actions that would ensure a more supportive policy and resource environment to spread and scale this model. This article summarizes the key findings from those listening sessions and recommendations to achieve Public Health 3.0.

Top

Introduction

The United States has made enormous progress during the past century in improving the health and longevity of its population through public health interventions and high-quality clinical care. In 2015, life expectancy at birth was 78.8 years, 10 years longer than in the 1950s (1). Smoking prevalence rates among adults and teenagers are less than half what they were 50 years ago (2). The proportion of people without health insurance is at a historic low of 8.8% (3). Health reform efforts have also improved health care quality and slowed the growth rate of health care costs.

However, this success falls short of ensuring that everyone in America can achieve an optimal and equitable level of health. The Centers for Disease Control and Prevention (CDC) recently reported that the historical gain in longevity in the United States has plateaued for 3 years in a row (4). Racial and ethnic disparities persist across many health outcomes and conditions, including life expectancy, infant mortality, and exposure to environmental pollutants (5). The gap in life expectancy between people with the highest and lowest incomes is narrow in some communities but wide in others (6). By mapping life expectancies in several cities across the United States, researchers illustrated that this metric can differ by as much as 20 years in neighborhoods just a few miles apart (7). These data suggest that investing in safe and healthy communities matters, especially for the most disadvantaged populations (8). However, many of these challenges require community-based interventions beyond health care. Indeed, today a person's zip code may be a stronger determinant of health than is his or her genetic code (7,9).

To solve the fundamental challenges of population health, we must address the full range of factors that influence a person's overall health and well-being. Education, safe environments, housing, transportation, economic development, access to healthy foods — these are the major social determinants of health, comprising the conditions in which people are born, live, work, and age (10). Fortunately, many pioneering communities across the country are already working to improve health by influencing these determinants in a positive way. From Nashville, Tennessee, to Manchester, New Hampshire, to Harris County, Texas, and the Shoalwater Bay Indian Tribe in Washington, community leaders have built coalitions to improve educational attainment, promote economic opportunity, ensure community safety, and build environments that promote mental health and community engagement.

Top

Key Influence of the Social Determinants of Health

Driven by payment policy changes, our health care system is transforming from one focused on episodic, nonintegrated care toward one that is value-based and would benefit from collaboration with allied community efforts. CDC developed a framework to conceptualize such integration across 3 areas of prevention— traditional clinical preventive interventions, interventions that extend care outside of the care setting, and population or community-wide interventions (11) (Figure 1). Although work in all of these areas is necessary to improve health, the work of Public Health 3.0 is focused on the second and third areas.

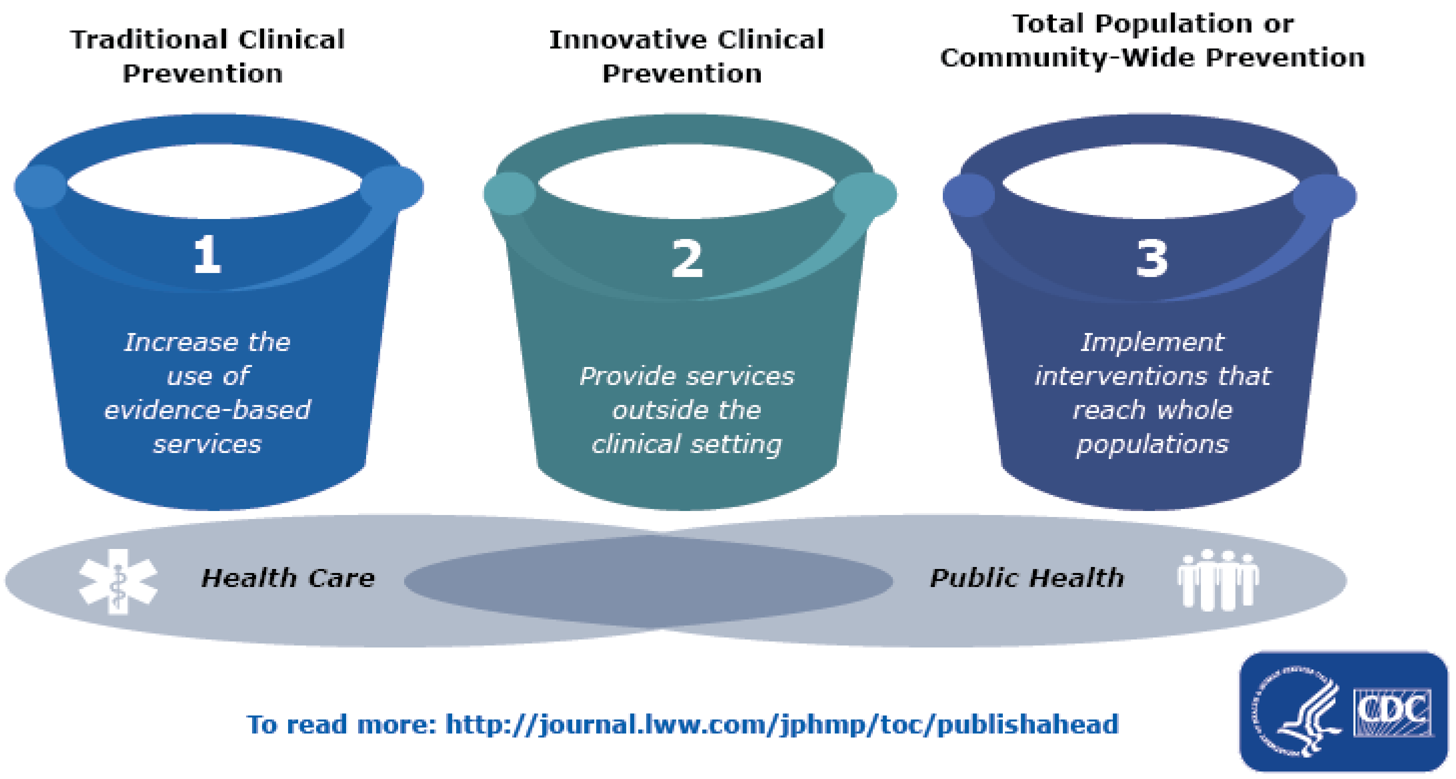

Figure 1.
Centers for Disease Control and Prevention's Three Buckets of Prevention. [A text description of this figure is also available.]

To improve the health of all people in America, we must also address factors *outside* of health care. Doing so means we must build on past successes and work across sectors to get closer to the essential definition of public health: *Public health is what we do as a society to ensure the conditions in which everyone can be healthy* (12).

Top

The Evolution of Public Health

This expanded mission of public health was underscored in the 1988 Institute of Medicine (IOM, now the National Academy of Medicine) report, *The Future of Public Health* (12). It is even more salient today. Pioneering communities across the country are demonstrating how this can be achieved, particularly when led by local public health departments (13).

The 2002 IOM report, *The Future of the Public's Health in the 21st Century* (14), called for strengthening governmental public health capabilities and requiring accountability from and among all sectors of the public health system. However, public health has been significantly underfunded. Relative to health care spending, the United States has made paltry investments in upstream, nonmedical determinants of health, such as social services, education, transportation, environmental protection, and housing programs. This lack of investment has had detrimental effects on population health (15). In addition, the 2008 recession precipitated a large and sustained reduction in state and local spending on public health activities (16). In 2012, nearly two-thirds of the US population lived in jurisdictions in which their local health department reported budget-related cuts to at least one critical program area (17).

Unfortunately, the need to strengthen the public health system, and the peril for failing to do so, is often only revealed in the context of disasters and crises. For example, in the aftermath of Hurricane Katrina, it became apparent that restoring health care services alone was insufficient in restoring New Orleans's health care system. The water crisis in Flint, Michigan, reminded us of the costly consequences of not placing health and environmental impacts at the center when making decisions that affect the public's health. For a community to address fundamental drivers of health while establishing readiness and resilience to crises requires a strong public health infrastructure, effective leadership, useable data, and adequate funding.

Top

Public Health 3.0: A Renewed Approach to Public Health

Public Health 3.0 builds on the extraordinary successes of our past (Figure 2). *Public Health 1.0* refers to the period from the late 19th century through much of the 20th century when modern public health became an essential governmental function with specialized federal, state, local, and tribal public health agencies. During this period, public health systematized sanitation, improved food and water safety, expanded our understanding of diseases, developed powerful prevention and treatment tools such as vaccines and antibiotics, and expanded capability in epidemiology and laboratory science. This scientific and organizational progress meant that comprehensive public health protection — from effective primary prevention through science-based medical treatment and tertiary prevention — was possible for the general population.

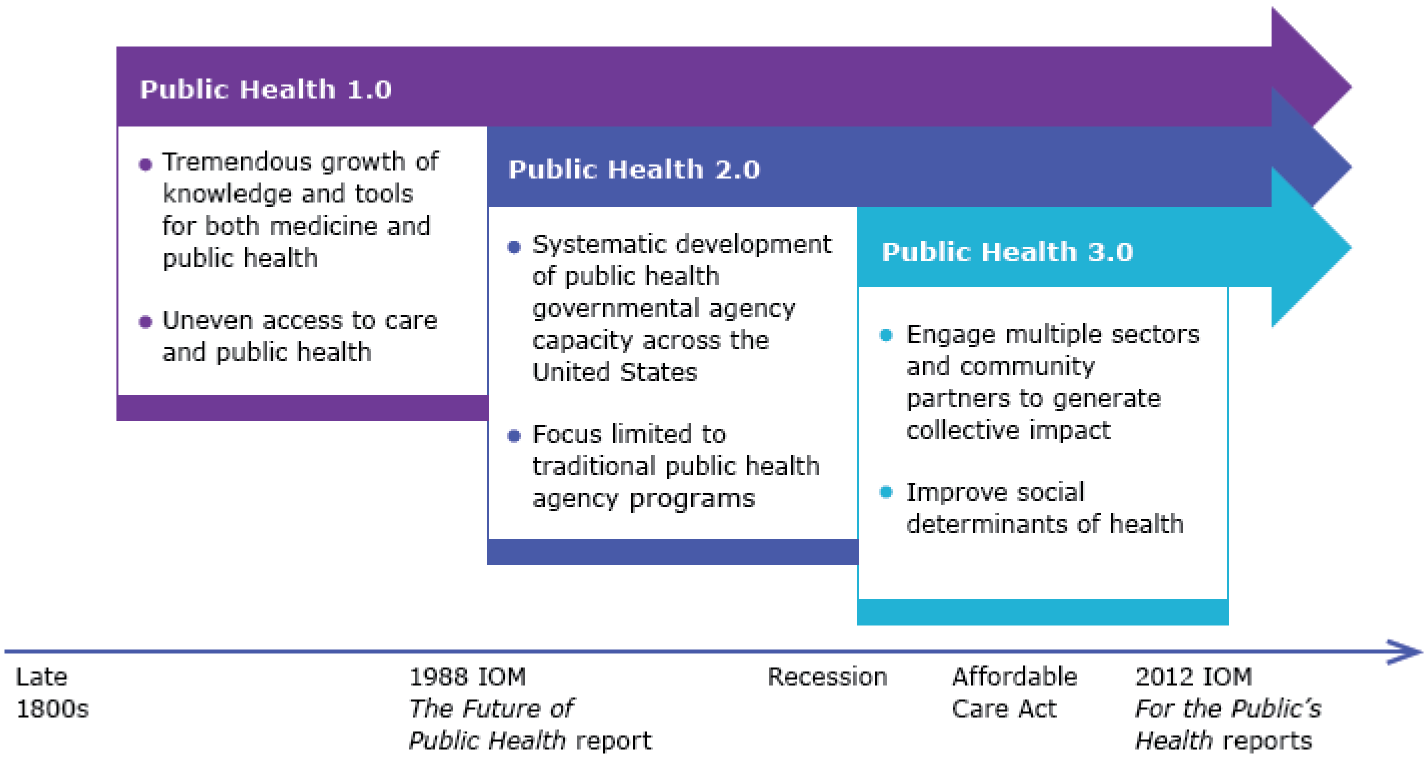

Figure 2.
Evolution of public health practices. Abbreviation: IOM, Institute of Medicine. [A text description of this figure is also available.]

Public Health 2.0 emerged in the second half of the 20th century and was heavily shaped by the 1988 IOM report *The Future of Public Health* (12). In that seminal report, the IOM posited that public health authorities were encumbered by the demands of providing safety-net clinical care and were unprepared to address the rising burden of chronic diseases and new threats such as the HIV/AIDS epidemic. The report's authors declared, "This nation has lost sight of its public health goals and has allowed the system of public health activities to fall into disarray."

With this call to action, the IOM defined a common set of core functions, and public health practitioners developed and implemented target capacities and performance standards for governmental public health agencies at every level. During the 2.0 era, governmental public health agencies became increasingly professionalized.

Public Health 3.0 refers to a new era of enhanced and broadened public health practice that goes beyond traditional public department functions and programs. Cross-sectoral collaboration is inherent to the Public Health 3.0 vision, and the Chief Health Strategist role requires high-achieving health organizations with the skills and capabilities to drive such collective action. Pioneering US communities are already testing this approach to public health, with support from several national efforts.

Top

Learning From the Field

At the core of Public Health 3.0 is the notion that local communities will lead the charge in taking public health to the next level and ensuring its continued success. Over the spring and summer of 2016, we visited communities across the United States to assess the accuracy of the 5 key components of the Public Health 3.0 framework and to hear firsthand what policy and other changes would support and sustain communities' Public Health 3.0 work.

We selected 5 geographically and demographically diverse communities and convened listening sessions with approximately 100 participants each. Each meeting showcased successful multisectoral collaboration designed to address the social determinants of health. The communities visited were Allegheny County, Pennsylvania; Santa Rosa, California; Kansas City, Missouri; Nashville, Tennessee; and Spokane, Washington. They were selected as representative of the broader Public Health 3.0 movement because of their national reputation for multisectoral collaboration, evidence of a strong local public health leader, innovative use of data and metrics, and funding. They also had experience in public health department accreditation. Allegheny County, Pennsylvania, is a prototype for the model including their work to form a structured partnership supporting health and blending and braiding funding across several governmental jurisdictions (18).

In these listening sessions, local leaders shared their knowledge, strategies, and ideas for successfully implementing Public Health 3.0–style initiatives. Meeting participants represented an array of expertise beyond public health and health care. Although participants noted unique challenges and successes in each region, many common themes emerged across the meetings.

Top

Recommendations to Achieve Public Health 3.0

Based on insights gathered from the public health community at these listening sessions, from conversations with leaders, and from a review of prior reports that lay out a framework for strengthening public health, we propose 5 broad recommendations that define the conditions needed to support health departments and the broader public health system as it transforms into the Public Health 3.0 model. A more detailed list of specific actions can be found in the Appendix and in the full report (18).

1. Public health leaders should embrace the role of **Chief Health Strategist for their communities —** working with all relevant partners so that they can drive initiatives including those that explicitly address "upstream" social determinants of health. Specialized Public Health 3.0 training should be available for the public health workforce and public health students.

   Although the local health officer often may serve in the role of Chief Health Strategist, there are circumstances in which such leadership comes from those in other sectors. Regardless, the public health workforce must acquire and strengthen its knowledge base, skills, and tools to meet the evolving challenges to population health, to be skilled at building strategic partnerships to bring about collective impact, to harness the power of new types of data, and to think and act in a systems perspective. This will require a strong pipeline into the public health workforce, as well as access to ongoing training and midcareer professional development resources.
2. Public health departments should engage with community stakeholders — from both the public and private sectors — to form vibrant, **structured, cross-sector partnerships** designed to develop and guide Public Health 3.0–style initiatives and to foster shared funding, services, governance, and collective action.

   Communities should create innovative and sustained organizational structures that include agencies or organizations across multiple sectors and with a shared vision, which allows blending and braiding of funding sources, capturing savings for reinvestment over time, and a long-term roadmap for creating health, equity, and resilience in communities.
3. Public Health Accreditation Board (PHAB) criteria and processes for department **accreditation** should be enhanced and supported to best foster Public Health 3.0 principles, as we strive to ensure that every person in the United States is served by nationally accredited health departments.

   As of August 2016, approximately 80% of the US population lived in the jurisdiction of one of the 324 local, state, and tribal health departments that has been accredited or is in the process of becoming accredited by the PHAB (19). The vision of ensuring that every community is protected by an accredited local or a state health department (or both) requires major investment and political will to enhance existing infrastructure. Although research found accreditation supports health departments in quality improvement and enhancing capacity (20), the health impact and return on investment of accreditation should be evaluated on an ongoing basis.

4. Timely, reliable, granular-level (ie, subcounty), and **actionable data** should be made accessible to communities throughout the country, and clear **metrics** to document success in public health practice should be developed to guide, focus, and assess the impact of prevention initiatives, including those targeting the social determinants of health and enhancing equity.

   The public and private sectors should work together to enable more real-time and geographically granular data to be shared, linked, and synthesized to inform action while protecting data security and individual privacy. This includes developing a core set of metrics that encompass health care and public health, particularly the social determinants of health, environmental outcomes, and health disparities.

5. **Funding for public health should be enhanced and substantially modified**, and innovative funding models should be explored to expand financial support for Public Health 3.0–style leadership and prevention initiatives. Blending and braiding of funds from multiple sources should be encouraged and allowed, including the recapturing and reinvesting of generated revenue. Funding should be identified to support core infrastructure as well as community-level work to address the social determinants of health.

   To secure sufficient and flexible funding in a constrained and increasingly tightening funding environment, local public health needs a concrete definition of the minimum capabilities, the costs of delivering these services, and a structured review of funding streams to prioritize mandatory services and infrastructure building.

Top

Early Action on the Recommendations

Upon the release of the report, several public and private organizations committed to advancing its recommendations. It was embraced by the American Public Health Association as the blueprint for the future of public health (21); others committed to developing training for Chief Health Strategists (22) or to building bridges between public health and the clinical care system, including payers (23). The US Department of Health and Human Services (HHS) implemented 3 priority recommendations, including extending reporting on accreditation status to federal public health entities, establishing a social determinants of health workgroup to support alignment of HHS policies, and launching a conversation about state-based opportunities to leverage health and human services resources to improve the public's health (23). Additionally, CDC's Health Impact in 5 Years (HI-5) initiative (24) provides nonclinical, community-wide toolkits to address social determinants of health that have demonstrated not only health improvement but also cost-effectiveness within 5 years. Community-level uptake and action through these resources could accelerate the impact of Public Health 3.0 collaborations.

Top

Key Barriers

For many communities, transforming to a Public Health 3.0 model will prove challenging. Although funding has stabilized, local health departments continue to face resource challenges from local financing streams, and proposals to reduce federal public health spending are likely to have a major impact at the local level (25). Despite promising advances such as the Big Cities Project, the absence of nonproprietary tools for data, analytics, metrics, and other uses leaves actionable information out of reach for most localities (25). Additionally, the daily challenges of meeting statutory public health responsibilities and a lack of experience and skill prevents most local health leaders from acting as Chief Health Strategists to bring people together across sectors. Finally, the basic foundational structure of local governmental public health may itself be a barrier to efficient and cost-effective coordination at the local level.

Top

Conclusion

The era of Public Health 3.0 is an exciting time of innovation and transformation. With the Public Health 3.0 framework, we envision a strong local public health infrastructure in all communities and its leaders serving as Chief Health Strategists that partner with stakeholders across a multitude of sectors on the ground to address the social determinants of health. With equity and social determinants of health as guiding principles, every person and every organization can take shared accountability to ensure the conditions in which everyone can be healthy regardless of race, ethnicity, gender identity, sexual orientation, geography, or income level. If successful, such transformation can form the foundation from which we build an equitable health-promoting system — in which stable, safe, and thriving community is a norm rather than an aberration. The Public Health 3.0 initiative seeks to inspire transformative success stories such as those already witnessed in many pioneering communities across the country. The challenge now is to institutionalize this expanded approach to community-based public health practice and replicate these triumphs across all communities, for the health of all people.

Top

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Top

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Top

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Appendix Top

Full List of Recommendations to Achieve Public Health 3.0.

Leadership & Workforce

- Public health associations such as Association of State and Territorial Health Officials (ASTHO) and National Association of County and City Health Officials (NACCHO) should develop best practice models and training for current public health leaders looking to work as Chief Health Strategists.
- The Health Resources and Services Administration (HRSA) should incorporate principles of Public Health 3.0 and social determinants of health in their workforce training programs, including the National Health Service Corps orientation, public health training center, and National Coordinating Center for Medicare and Medicaid Services Accountable Health Communities Model.
- Local public health agencies should partner with public health training centers and academic schools and programs of public health to inform training that meets the local public health workforce needs.
- The business and public health communities should jointly explore leadership development and workforce enrichment opportunities such as short-term fellowships or exchange programs, with a particular focus on the financial and operational capacity of local health departments.
- Academic institutions should encourage their faculty and administrations to develop meaningful partnerships with local public health departments and support service learning and internships for students from all disciplines in state and local health departments.
- Local health departments should train their leaders and staff in the concept and application of the collective impact model of social change.
- Public health should work with leadership institutes and business schools to establish professional development resources and opportunities.

Strategic Partnerships

- Local public health agencies should form cross-sector organizational structures aimed at achieving a collective vision of community health that are capable of receiving and sharing resources and governance.
- The US Department of Health and Human Services (HHS) should work with others to develop a report defining the key characteristics of successful local public health models that address social determinants of health through cross-sector

partnerships and recommending pathways to wide adoption.

- The Assistant Secretary for Preparedness and Response (ASPR) and the Centers for Disease Control and Prevention (CDC) should work with state and local health entities to ensure synchronization between health care practices, coalitions, and public health entities. Pre-crisis collaboration is essential to improve sharing of limited resources, improve timely and accurate communication, and improve sharing of data relevant to preparedness planning and response.
- Local public health leaders should create cross-jurisdictional organizational structures or partnerships for community development efforts.
- Public health entities should partner with environmental health agencies to address the environmental determinants of health.
- HHS should continue to develop tools and resources (such as the HI-5 [Health Impact in 5 Years]) that identify system-level drivers of health disparities, connecting health and human services, and work with communities to translate evidence to action.
- HRSA should recommend that health centers document collaboration with their state and/or local health department.
- Health care providers should identify clear mechanisms to engage with local public health as part of their effort to achieve the three-part aim of better care, smarter spending, and healthier people.
- The Centers for Medicare and Medicaid Services (CMS) and ASPR should work together to ensure state and local public health entities engage health care providers during times of crisis or disaster. Preparedness measures are essential to healthier and more resilient people.
- The Substance Abuse and Mental Health Services Administration should encourage state mental health and substance use disorder agencies and other grantees to collaborate with state, local, and tribal public health entities in achieving PH3.0 goals.
- The Agency for Healthcare Research & Quality should ensure linkages between primary care and public health via the Primary Care Extension Program and evaluate outcomes.
- The National Institutes of Health should continue its community participatory research and engagement efforts, such as the Clinical and Translational Science Awards and the Partnerships for Environmental Public Health, to accelerate translation of evidence to community action, as well as to generate new knowledge in the evaluation and implementation of public health interventions.
- Public health leaders should pursue local partnerships to ensure population health is central in all community development efforts.

Infrastructure and Accreditation

- HHS should assess opportunities to incentivize Public Health Accreditation Board (PHAB) accreditation through federal programs and policies.
- HHS should require state and local health departments receiving federal grants to indicate their PHAB accreditation status, including applications in progress or plans to apply in the future.
- The federal government should partner with the private sector to create a learning community for local health departments seeking to engage in PH3.0 work with a particular focus on collective impact models to address the social determinants of health.
- Resources to support the accreditation process and maintenance should be more readily available from public and private funding sources.
- PHAB should continue to evolve accreditation expectations by incorporating Public Health 3.0 concepts.
- Philanthropic organizations supporting local public health activities and social interventions should require grant applicants to collaborate with local health departments.
- ASTHO and NACCHO should accelerate their support of state and local health departments moving to accreditation.
- PHAB and its strategic partners should continue to enable pathways to accreditation for small and rural health departments.
- States should assess the efficiency and effectiveness of their local health departments, including addressing jurisdictional overlaps and exploring opportunities for shared services mechanisms.

Data, Metrics, and Analytics

- HHS should utilize opportunities such as Healthy People 2030, NCVHS's population health subcommittee, the Evidence-Based Policymaking Commission, and the census to elevate metrics related to social determinants to be leading health indicators, to define community-level indicators that address the social determinants of health and to explore models to leverage administrative data.
- NCVHS should advise the secretary of HHS to incentivize the integration of public health and clinical information.
- CDC should continue its work with the private sector to make subcounty-level data including health, health care, human services, environmental exposure, and social determinants of health available, accessible, and useable.
- HHS should work with public health leadership and the private sector to develop a nonproprietary tool to support geographic information systems and other analytic methods for front-line public health providers.
- Health systems and other electronic health data repositories should prioritize data sharing at the federal, state, and local level with the goal of achieving a learning health system inclusive of public health by 2024 as described in the Office of the National Coordinator for Health Information Technology (ONC) Nationwide Interoperability Roadmap.
- The HHS Office for Civil Rights should continue to develop guidance for the public health system to provide clarity on private and secure data use, as well as guidance to promote civil rights compliance to address those social determinants which are the product of discriminatory practices.
- ONC and the Administration for Children and Families should continue to establish clear data and interoperability standards for data linkage between health and human services sectors.
- HHS should continue to identify gaps in the collection of data relating to race/ethnicity, language, gender identity or sexual orientation in existing surveys. When feasible, governmental and nongovernmental stakeholders at all levels — federal, state, local, and tribal — should collect standardized, reliable data concerning disparities.
- HHS should facilitate linking environmental and human services data to health.

Sustainable and Flexible Funding

- The CMS and private payers should continue to explore efforts to support population-level health improvements that address the social determinants of health.
- HHS should explore transformation grants for state and local health departments to evolve toward PH3.0 structure, analogous to the State Innovation Model (SIM) grants to support health care system transformation.
- State governments receiving funds through SIM or Medicaid Waiver processes should be required to document their health department accreditation status and their strategies for addressing the social determinants in partnership with their local public health departments.
- States should maximize their use of the funding through the Health Services Initiative option under the Children's Health Insurance Program to advance their public health priorities for low-income children.
- HHS should enhance its coordination both within the department and with other agencies, developing and executing cross-agency efforts to strategically align policies and programs that address the social determinants of health.
- Public and private funders should explore options to provide more flexibility for accredited health departments to allocate funds toward cross-sector efforts including partnership development and collective impact models in addressing the social determinants.
- Communities should examine how to best use the Affordable Care Act's community benefits requirement for nonprofit hospitals by coordinating the alignment of the data collection process and pooling resources and how these can be used to advance and provide funding for public health.
- Public health agencies and academic institutions should periodically calculate the funding gap — the difference between the costs of providing foundational capabilities by each local health department and its current funding level — and communicate these figures in the context of forging partnerships and expanding funding sources.

Top

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Charting a Course for an Equity-Centered Data System:

Recommendations from the National Commission to Transform Public Health Data Systems

OCTOBER 2021

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TABLE OF CONTENTS

A Statement from Dr. Richard E. Besser

Public health data should reflect the needs of everyone in America—regardless of their race, where they live, or how much money they have. If we are to become a nation that truly values health equity, public health data must reflect fairness, justice, and inclusion as fundamental requirements.

That's why, as the nation's largest health philanthropy, the Robert Wood Johnson Foundation (RWJF) convened the first-of-its-kind National Commission to Transform Public Health Data Systems. The Commission was charged with reimagining how data are collected, shared, and used, and identifying what public and private sector investments are needed, with the express purpose of improving health equity.

The COVID-19 pandemic laid bare the deficits of our public health infrastructure. It forced us to acknowledge that we must modernize our data systems—and we must act fast. Due to incomplete and disparate data collection, it took far too long to see the disproportionate impacts of the pandemic on Black, Latino, and Indigenous communities. Lack of reliable data collection on factors that matter for health equity and lack of consistent and transparent reporting of these data impeded us from saving lives and affected our ability to ensure that those hardest hit by COVID-19 were prioritized at every stage of the pandemic—from testing to hospitalization to vaccination.

The U.S. Centers for Disease Control and Prevention, along with more than 200 state and local jurisdictions, have declared racism a public health crisis. Reforming our public health systems to address structural racism requires that we collect and analyze data in ways that accurately reflect the serious harms that racism and other forms of discrimination inflict on our communities. That means taking a hard look at our data systems and asking who the data we collect elevates, who is being centered in our data, who is being excluded, and why.

The Commission, a diverse group of 16 members with expertise in areas including healthcare, advocacy, government, business, and public health asked those questions and more. Together, these leaders considered a broad range of actionable solutions for strengthening our public health systems to embrace innovation, inclusion, and anti-racism. The recommendations set forth in this report amount to a blueprint for building a robust 21st century public health data system that advances health equity and equips us to address the racism embedded in our current infrastructure.

It's impossible to fix what isn't measured. We have an opportunity now to create a data infrastructure that is centered on equity and that creates fair and just opportunities for everyone. Let's take that opportunity to promote health and well-being for everyone in America.

RICHARD E. BESSER, MD
President and CEO
Robert Wood Johnson Foundation

SUMMARY OF RECOMMENDATIONS

Center health equity and well-being in narrative change

- Identify the stakeholders in public health data system transformation and how to engage them at each step of the transformation process.
- Build on stakeholder identification and develop a campaign to promote the importance of public health data and the need for a transformed public health data system.
- Develop a competencies framework to increase data literacy for various stakeholders about the importance of equity considerations in data systems.
- Build the public health data system needed to shift the narrative to one that is just, positively oriented, and equity-based (e.g., from deficit to strengths, from oppressive to restorative).

Prioritize equitable governance and community engagement

- Prioritize and accelerate implementation of the Evidence Act (Foundations for Evidence-Based Policymaking Act of 2018) for improved transparency, quality, and availability of data.
- Establish and implement a coordinated state and federal investment strategy that includes regular fiscal support of state infrastructure coupled with intermediate and long-term system development and data collection.
- Generate and sustain system transformation with defined governance and stewardship models and structures.
- Make sharing and pooling data (at both the individual level and system level) the default for agencies receiving public money and provide data to all actors.
- Build efficient and interoperable data systems to generate comprehensive, complete, and timely data. Collect data with adequate granularity across population groups (inclusive of race/ethnicity, language ability, disability) and geographic levels that are useful at the community level and can be aggregated and disaggregated.
- Develop agile, analytical methods to work with existing data sets and across diverse sets of quantitative/qualitative data, including historical data.
- Technology companies should support public health data system transformation in under-resourced areas of the country with the largest health inequities, either by direct financial support (corporate social responsibility-CSR) or through skills-based volunteer approaches.
- Philanthropy should fund gaps in public health data, particularly for communities with less resources.

Ensure public health measurement captures and addresses structural racism and other inequities

- Build on the Executive Order (EO) on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government: Equitable Data Working Group, to establish an Interagency Data Council, with responsibility for equity, racial justice, & social and public health data.
- As part of public health data system redesign, collect self-reported data by race, ethnicity, income, education, gender identity, sexual orientation, disability, and social position (i.e., how people are placed in a hierarchy of value by society, as perceived by the individual).
- Invest in community relevant and nationally significant metrics on factors that influence health outcomes.
- Collect data that are more accurate and relevant at the community level to enable small area estimates that enable communities and local health departments to prioritize and address local health challenges and measure progress towards healthier communities.
- Develop methods for interpreting public health data that are inclusive of community input, paying attention to messaging, communication, and narrative.

CALL TO ACTION SUMMARY

Government as well as private and other civil society sectors have a role to play in transforming our public health data system.

SECTOR	ACTION
FEDERAL GOVERNMENT	▪ Develop minimum standards about data collection, disaggregation, presentation, and access, in federally funded data collection efforts, with an orientation to "freeing federal data" or promoting greater access. ▪ Strengthen public health data infrastructure and incentivize the use of new data collection and analytic approaches. ▪ Federal funding for data infrastructure should be prioritized to systems that are standards-based and interoperable. ▪ Offer guidance on interpretation of racial/ethnic variation in health-relevant data to counter longstanding acceptance of the idea that these variations reflect biological differences rather than systemic, cultural, behavioral, and social factors.
STATE GOVERNMENT	▪ Ensure that state policies for public health data collection, sharing (including balancing privacy and transparency), and analysis are equity driven and explicitly call out the influence and consequences of structural racism and other inequities on health. ▪ Partner with local health departments and departments that provide public health data (e.g., social services data) to consider new models of collaboration to improve efficiency and timeliness of decision-making and action at both state and local levels.
LOCAL GOVERNMENT	▪ Regularly connect public health data to local communications (i.e., what is happening in the community and how it relates to overall community well-being, or the impact of inequity). ▪ Ensure the local voice is represented not only in public health data (e.g., from whom data are collected), but in positions of authority responsible for making sense of the data and informing decisions. ▪ Explore data-sharing collaborations across government and civil society (e.g., nonprofits, businesses) that can more consistently generate public health data to support equity considerations and advance innovative public-private collaborations on data and analysis.
PUBLIC HEALTH	▪ Lead multisector collaboration around public health data sharing to improve the timeliness and quality of data to strengthen local decision-making. ▪ Strengthen capacity, diversity, and ongoing training of the public health workforce to monitor and address health equity, both in the field of public health and through novel collaborations with business, academia, or other sectors that influence health. ▪ Advocate for and prioritize modernization efforts and data sharing within and across the public health system to ensure that local data can inform emerging public health concerns at the regional, state, and national levels in real time.

BUSINESSES	▪ Work with government partners and other organizations to develop standards through which public health data generated by the private sector can be used and communicated. ▪ Engage in more consistent workforce exchanges and data partnerships with public health organizations to cross-pollinate innovations in the types, content, quality, and precision of public health data. ▪ Foster public health innovation by promoting methods in use by technology companies, such as data integration, “big data” analytics, and data security.
HEALTHCARE SYSTEMS	▪ Collect social determinants of health data at every consumer encounter, using standardized questions and ICD-10 codes that allow data aggregation within communities. ▪ Overcome historic silos and build partnerships and legal solutions to facilitate sharing of relevant healthcare data with public health departments in a timely and efficient manner, allowing data linkages and disaggregation of subgroups and geographic regions.
NONPROFITS	▪ Build trust in data as a public good in the community and among constituents and ensure that such data do not further marginalize or bring harm to populations. ▪ Work locally to develop data-sharing strategies with government, and, where appropriate and where there is health benefit, reciprocity, and equitable access.
PROFESSIONAL ASSOCIATIONS	▪ Develop strategies to improve data completeness and quality, particularly with respect to equity and drivers of health and well-being. ▪ Actively work with professional associations from other sectors that influence health (e.g., education, social services, environment) to align efforts, particularly around standardization and data use.
SCHOOLS	▪ Help students monitor and evaluate structural and systemic inequities and understand what data systems must include to signal those inequities. ▪ Train the next generation of public health practitioners and researchers to meaningfully partner with local stakeholders, and to value lived experience and community expertise as much as formal training
PHILANTHROPY	▪ Promote a national, unifying health goal that can be understood and executed, with a focus on the role of structural racism and the values of health equity and well-being. ▪ Leverage convening and funding opportunities to meaningfully engage leaders, including those from non-health sectors and community organizations, who can advance the importance of public health data. ▪ Focus funding on key parts of data systems modernization, such as improving governance and using new forms of data and analytic methods to convey better stories of health equity and well-being.

INTRODUCTION

Public health data and data systems are essential to achieving health and racial justice.

Public health data and data systems take the pulse of our society; they measure and indicate how well we sustain the life and vitality of our population and our democracy. As such, these data and systems include governmental public health data and data from many other sectors (e.g., environment, criminal justice, human services, employment, education) and levels (e.g., community, state, nation) that can inform efforts to improve health equity and well-being. Data are the building blocks of population health narratives—stories that emerge from data—that help the nation contextualize what drives or impedes health. What data are collected and how data are collected and interpreted shape these narratives. Data help us identify and understand the magnitude of and reasons for inequity in outcomes and the influence of structural factors like racism and other forms of discrimination on the ability to live a healthy life. To be meaningful, data must reflect accurate and timely information about all population groups and their individual and collective capacities to experience health and well-being.

The year 2020 revealed significant flaws—indeed, fault lines—within our public health data systems' capacity and infrastructure. COVID-19 exposed these problems explicitly as lack of transparency, conflicting information, and inconsistent and often missing data sowed public distrust, confusion, uncertainty, and fear about individuals' and the nation's current and future health.

Now is the time for a reset.

Inequities in exposure to COVID-19, illness, and death accelerated awareness of the need to address the disparate health opportunities for diverse racial, ethnic, and other marginalized populations, including immigrants, people with disabilities, returning citizens, and the LGBTQ+ community. This developing awareness was amplified by our collective witness to the brutal murder of George Floyd, an unarmed Black man, by a White police officer. Mr. Floyd's murder was not an isolated event. However, it catalyzed nationwide recognition that the relentless killings of unarmed persons of color by police and the racial inequities in COVID-19 infection, illness, and death were both manifestations of structural racism—or laws, policies, cultural representations, and norms across interconnected systems that support the unfair treatment of some groups based on the social construct of race that is grounded in a false ideology of a hierarchy of human value.

An unprecedented level of public protest that united people of all races in calling for racial reckoning and justice gives the United States an opportunity to fundamentally change public narratives and institutional policies. Three co-occurring crises (COVID-19, structural racism, and economic disruption for millions of Americans with low incomes) all signal the need for data that can shed light on the structure and intersectional dynamics involved in improving health and well-being and help reframe the national narrative to one that is just, positively oriented, and focused on equity (e.g., from deficit to strength, from oppressive to restorative) from one that is deficit focused.

At the same time, we continue to face many emerging new threats. For example, life expectancy in the United States departed from the trajectory of other wealthy nations decades ago and has dropped in recent years. COVID-19 has fueled that decline. This drop has disproportionately affected people of color, reversing decades of progress in reducing the racial mortality gap.[1]

In our current data system, data on health inequities are decontextualized from history and the experiences of race, intersectionality, and place that impact health. Although current systems report on health status and disparities, data can perpetuate health inequities when they lack appropriate context for understanding the root causes of those inequities. We need compelling, inclusive information to help drive critically needed actions and policies. The challenges before us are:

- Can we improve data to capture the many drivers of health and the nuances of lived experience to help direct a hopeful future for America's many diverse communities?

- Are the required human, financial, and technical resources available and targeted within, across, and among sectors to develop these data?

- Now that the U.S. Centers for Disease Control and Prevention (CDC) and more than 200 local health departments have declared racism a public health crisis, how can our governmental and broader public health data systems provide the information and tools we need to work together with partners in healthcare, business, labor, academia, philanthropy, faith institutions, and communities to address this crisis effectively?

The National Commission to Transform Public Health Data Systems addressed these issues and challenges during its recent deliberations. Convened by the Robert Wood Johnson Foundation (RWJF), the 16-member Commission was charged with reimagining how data are collected, shared, and used, and identifying the public- and private-sector investments needed to modernize our public health data infrastructure and improve health equity. This report summarizes the recommendations that emerged from the Commission's deliberations. The report is organized in the following sections.

PART 1 of the report presents the Commission's recommendations, organized into three major themes. The first theme, **Health Equity and Well-Being Narrative Change**, includes recommendations that emphasize the importance of centering public health as the nation's pathway to better health and well-being. These recommendations focus on building support among a broad array of stakeholders for a new public health data system that advances health equity, creating the messaging needed to promote the role of data in this process, preparing stakeholders and the workforce to achieve this change, and beginning to create new systems and infrastructure. The second theme, **Equitable Governance, Systems, and Community Engagement**, focuses on the data stewardship, technology, and partnerships needed to transform the system. This section addresses the regulatory, technical, and collaborative work that must be done to create a data system with the breadth, capacity, and specificity needed to understand what drives health and to promote evidence-based decision-making. The **Measuring and Addressing the Health Impact of Structural Racism and Other Inequities** theme addresses the changes needed to redress contemporary and historic health effects of racism and other systemic barriers to opportunity for diverse groups. This section focuses on relationship-building and the types of data needed to transform the system.

Part 1 also includes an **Introduction** that describes the urgency of these changes, the current landscape, and the opportunities for transformation.

PART 2 of the report describes the steps taken and knowledge gained in preparation for the Commission process. RWJF commissioned the RAND Corporation to produce a series of white papers that anchored this process by describing the current landscape, emerging innovations, and the opportunities for transforming and transitioning to a new public health data system. The papers were informed by an environmental literature scan, review of reports on public health data transformation, and stakeholder interviews. In addition, the papers included insights from 20 organizations that received RWJF grants for innovative work related to data equity and data systems integration. The formative work also included focused discussions with five expert panels on population-specific data gaps (American Indians/Alaska Natives, Blacks/African Americans, LGBTQ+ communities, people living with disabilities, and women). The section goes on to describe the formation of the Commission, the adaptation of the Truth, Racial Healing, and Transformation (TRHT) framework used during the Commission's deliberations, and the Commission's work to create a new vision for transforming the public health data system and its recommendations for achieving that vision.

PART 3 presents a call to action for various sectors and stakeholders, including federal, state, and local governments, and businesses, health systems, nonprofits, schools, associations, and philanthropy. This section provides a preliminary blueprint of when, how, and by whom actions can be taken to implement and advance and build on these recommendations.

What is a modern, transformed public health data system?

The Commission defines a transformed public health data system as one that is accountable to and reflects the perspectives of local communities and diverse populations, including people of color, immigrants, persons with disabilities, and the LGBTQ+ community. The system must be sustainable, fully integrated with healthcare and other sectors that drive health by linking data across multiple sectors and at multiple levels, and provide data that are disaggregated, comprehensive, and timely. It should move from problem-focused to solution-focused analysis and have the capacity to provide the knowledge needed to optimize health and well-being for all people. It must provide tools to address racism and racial/ethnic and other social disparities. It should facilitate restorative systems that respect all communities, including the sovereign right of tribal nations to govern data and ensure they have access to it; protect individuals' privacy and security; and guard against unintended consequences.

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RECOMMENDATIONS

1. Center Health Equity and Well-Being[a] in Narrative Change

The approach to collecting, analyzing, and using public health data must be motivated by a new narrative that prioritizes health equity and factors in all of the physical, social, mental, cultural, economic, and environmental drivers of health and well-being. A modern and transformed public health data system would address structural racism, equity, and well-being considerations as the guiding influence in all data-informed decisions.

> “Data speaks, it sings, it carves, it paints. And how we tell the story is very powerful.”
>
> – Commissioner Abigail Echo-Hawk

Recommendation 1a. Identify the stakeholders in public health data system transformation and how to engage them at each step of the transformation process.

CONTEXT. A modern, equity-oriented public health data system should mobilize the full range of actors and sectors that influence health outcomes, help identify health priorities, and catalyze action. There is growing evidence about the benefits of having full community and multisectoral participation in public health decision-making.[3] But too often groups that have been marginalized and disproportionately affected by health inequities are excluded.[4] In the context of new forms of data or “big data,” issues of participation and representation are even more critical.[5] Best practices for community engagement must be used to facilitate authentic engagement and empower community members and stakeholders.

WHAT NEEDS TO BE DONE

SHORT-TERM

- Map the power, expertise, and authority dynamics that shape public health data systems and engage all stakeholders as partners in the transformation.

LONG-TERM

- Enable active and sustained community engagement in public health discussions and decisions around public health data system design, content, and use. For example, ensure consistent representation from a range of leaders, including community-based leaders and advocates, and across sectors (e.g., housing, economic development, environment, criminal justice, education, disability rights).

WHO NEEDS TO ACT

- Government leaders
- Tribal leaders
- Health care systems
- Private sector/Business leaders
- Media leaders
- Philanthropies
- Community-based organizations
- Academia/Research institutions
- Advocates for diverse communities and population groups

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[a] “Well-being means thriving in every aspect of life and having opportunities to create meaningful futures. It includes people’s physical, mental, and social health, as well as basic needs like food, housing, education, employment, and income. It includes social and emotional needs, like sense of purpose, safety, belonging and social connection, and life satisfaction. It must include freedom from racial oppression, and active advancement of racial equity. The concept is tightly linked with the well-being of our communities, our environment, and our planet. While it often has been incorrectly considered an individual wellness concept, well-being goes far beyond that by considering relationships among people, interconnectivity of cultures and societies, and relationships between people and the planet.” From: Setting a new narrative about progress and well-being, RAND and Metropolitan Group, August 2021.

Recommendation 1b. Build on stakeholder identification and develop a campaign to promote the importance of public health data and the need for a transformed public health data system.

CONTEXT. Much of what are currently considered public health data is stored by local public health departments, healthcare organizations, and other entities outside health that generate social determinants of health (SDOH) information. These data are not fully available or accessible for the diverse stakeholders comprising the broader public health system. Thus, the value of public health data is not always well understood. Further, many sources of public health data fall outside of health (e.g., departments and organizations related to social services, economics, environment). A public health data system should ensure open access where appropriate, provide supporting materials to support meaningful engagement with data, link to actionable policy and programmatic solution options, be designed to invite access and usability, and be useful to people working to improve health in their communities.

WHAT NEEDS TO BE DONE

SHORT-TERM

- Develop case studies that explain the story and the value of public health data. Potential case studies include the 2020 Census, which showcases how data drive resource allocation, and COVID-19, which can illuminate the role of data in tracking a global pandemic.
- Develop messaging aimed at different audiences about the value of public health data and modernizing the public health data system. Use microtargeting, representative storytelling, and economic framing (meaning tighter links between public health, economics, and well-being) to carry out messaging and subsequent campaigns.
- Identify diverse leaders (e.g., from professional associations, grassroots organizations), across all U.S. geographies and subgroups, who will serve as campaign ambassadors and prepare them for that role.

LONG-TERM

- Highlight the important role of collecting and analyzing public health data for implementing equitable public policy.
- Continue to emphasize the value of public health data and its linkage with community and national progress.

WHO NEEDS TO ACT

- Government leaders
- Tribal leaders
- Private sector/Business leaders
- Media leaders
- Professional associations (e.g., National Association of County and City Health Officials, American Hospital Association, National Association of Community Health Centers and American Essential Hospitals, American Medical Association)
- Philanthropies, such as RWJF
- Academia/Research institutions
- Grassroots and community leaders

Recommendation 1c. Develop a competencies framework to increase data literacy for various stakeholders about the importance of equity considerations in data systems. This framework also can deepen understanding of the value of public health data, shift perceptions about what constitutes public health data and who has access to them, and explore how data can motivate public health data system transformation.

CONTEXT. There is growing concern that the public health workforce lacks the core skills and competencies to procure and optimize information technology. Individuals skilled in informatics are choosing private industry over public health for better pay and advancement. The public health workforce could benefit from expanding analytic competencies through a multipronged approach (e.g., school course offerings, narratives about innovation in public health data, and workforce exchanges with the private sector) to build competencies and fill this gap. Several federal policies (e.g., 2020 Federal Data Strategy[6]) can be leveraged for this workforce support.

> “Misinformation is a serious issue. It is important we create an environment where all communities trust data.”
>
> – Commissioner Michael Crawford

WHAT NEEDS TO BE DONE

SHORT-TERM

- Train the public health data workforce to understand why equity should be embedded in the content, structure, analysis, translation, presentation, access, use, and dissemination of data.
- Make sure the workforce embraces diverse perspectives on how to shift data and their accompanying narratives toward health equity and well-being.

LONG-TERM

- Permanently shift the public health narrative by integrating the value of public health data and their role in social change into the curriculum of graduate/undergraduate schools (e.g., public health, social work, health professions, public policy, economics, sociology, political science, business, environmental science) and other training programs.

WHO NEEDS TO ACT

- Federal government leaders
- Public health departments
- Health care systems
- Private sector/Business leaders, particularly from technology and data generation companies
- Professional associations
- Philanthropies
- Academia/Research institutions

Recommendation 1d. Build the public health data system needed to shift the narrative to one that is just, positively oriented, and equity-based (e.g., from deficit to strengths, from oppressive to restorative).

CONTEXT. The current public health data system disproportionately focuses on negative health outcomes (e.g., mortality and morbidity), and overlooks positive health and well-being measures (e.g., community cohesion, hope, civic engagement, prosocial behaviors, resilience). Without such information, the nation cannot track aspects of thriving and flourishing that are central to health and well-being. A future public health data system also must monitor the processes and outcomes of inequity, history, cumulative risk, and cumulative trauma on health.[7] The modern public health data system must look both upstream, at the structural drivers of health inequities, and over time, at intergenerational inequities.[8,9]

WHAT NEEDS TO BE DONE

SHORT-TERM

- Assess gaps in the current data system (e.g., standard race/ethnicity reporting at different levels of government and across agencies, user interface, security and privacy, usability for different languages and literacies), and how these gaps may impede a more holistic and equity-centered public health narrative.
- Identify minimal datasets to tell narratives of equity that are specific to the needs and context of diverse communities (e.g., immigrants, individuals who are incarcerated, people released from prison, people not actively seeking employment or housing or healthcare, people with disabilities) as well as to address issues of race/ethnicity, disability, language access, and American Sign Language (ASL) needs.

LONG-TERM

- Create specific protocols and multiple use cases[b] for a transformed public health data system that supports restorative[c] and prospective storytelling. Data should be complete enough to showcase history and context, how communities respond to challenges, and should feature community voices.
- Use those cases to inform public health data narrative change strategies. For example, how accurate representations of diverse communities and the effects of the COVID-19 pandemic are utilized to foster timely and appropriate responses to needs.
- Ensure that efforts to increase public health infrastructure capacity prioritize support for building an effective public health data narrative focused on health equity and well-being.

WHO NEEDS TO ACT

- Office of the National Coordinator for Health Information Technology (ONC), Department of Health and Human Services (HHS)
- White House, Data Equity Working Group and Office of Management and Budget (OMB)
- Private sector/Business leaders, particularly from technology companies
- Hospital associations
- Philanthropies
- Academia/Research institutions
- Other members assembled through a Federal Advisory Committee process

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b. A use case is a description of all the ways an end-user wants to “use” a system..

c. Restorative storytelling is an approach to storytelling in which descriptions show how people and communities respond and recover after difficult times; these stories do not just focus on challenges.

2. Prioritize Equitable Governance and Community Engagement

A modern public health data system must execute a plan for governance, decision-making, and community engagement that centers addressing structural racism and creating equity in its design and operation. This means transparency, accessibility, and interoperability in all aspects of how the public health data system runs, how the system interacts with other systems, and how it takes in new information to respond to emerging and ongoing health issues.

Recommendation 2a. Prioritize and accelerate implementation of the Evidence Act (Foundations for Evidence-Based Policymaking Act of 2018) for improved transparency, quality, and availability of data.

CONTEXT. The Foundations for Evidence-Based Policymaking Act (Public Law No: 115-435)[10] requires agency data to be accessible and requires agencies to plan to develop statistical evidence to support policymaking. It also includes the OPEN Government Data Act, which “requires public government data assets to be published as machine-readable data” and an online federal data catalogue and “a single point of entry for the public to access agency data.”[11] (These laws do not apply to tribal nations.) Accelerating the law’s implementation would provide federal momentum for an equity-oriented data system. Other federal activities to address equity and upstream drivers of health could be further leveraged to strengthen the public health data system. Examples include:

- **EXECUTIVE ORDER (EO) ON ADVANCING RACIAL EQUITY AND SUPPORT FOR UNDERSERVED COMMUNITIES.** This EO calls for data to be disaggregated by race, ethnicity, gender, disability, income, veteran status, or other key demographic variables to advance equity.[12]
- **INTERDEPARTMENTAL HEALTH EQUITY COLLABORATIVE (IHEC) DATA WORKGROUP.** The IHEC Data Workgroup includes experts engaged in data activities and data policies to address SDOH and health disparities. The goals of the group are to identify existing policies and practices for improving access to data and use of data in support of policy development and to promote data projects and applications that address SDOH and support efforts to advance health equity.[13]

WHAT NEEDS TO BE DONE

SHORT-TERM

- Integrate Commission recommendations with the above efforts, leveraging Commissioner connections and positions on various workgroups.

LONG-TERM

- Advocate for and support federal, state, and local policies that promote transparency, quality, and availability of data in a manner that also respects indigenous data sovereignty, which is the right of a nation to govern the collection, ownership, and application of its own data. It derives from tribes’ inherent rights to govern their people, lands, and resources.[d]

WHO NEEDS TO ACT

- Federal government leaders
- Tribal leaders
- Academia/Research institutions
- Transforming Public Health Data Commissioners, in supporting role

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[d] https://usindigenousdata.org/

Recommendation 2b. Establish and implement a coordinated federal, state, and local investment strategy that includes regular fiscal support of state infrastructure coupled with intermediate and long-term system development and data collection.

CONTEXT. General federal and state funding for public health has declined over the past decade.[14] The resulting wide variability in public health infrastructure has had critical cascading effects for health equity.[15] Key to achieving an equitable health data system is assessing how to migrate legacy data systems to efficiently participate in any data sharing model with minimal human effort and securing the funding and other supports needed to sustain these new systems. For example, COVID-19 has driven the rapid adoption of electronic case reporting, which could immediately add data about more than 100 notifiable and reportable conditions. However, state agencies with multiple legacy surveillance systems often cannot receive and parse this real-time reporting.[16] Although federal policy and funding can shape a new vision of a modern, equity-oriented data system, state governments can reinforce the value of equity orientation in data or counter them through restrictive policies and narrow resource allocation decisions.

WHAT NEEDS TO BE DONE

SHORT-TERM

- Secure short-term investment in infrastructure, including technology and necessary human capabilities, to leverage data for decision-making.

LONG-TERM

- Secure longer-term investments to migrate legacy data systems and ensure that systems are sustained and maintained.

WHO NEEDS TO ACT

- Federal government leaders
- State government leaders
- Private sector/Business leaders

Recommendation 2c. Generate and sustain system transformation with defined governance and stewardship models and structures. These should sustain and hold accountable a transformed data system that supports equitable and just narratives and inclusive decision-making.

CONTEXT. The rapid pace of innovation in information technology and changes in what, how, when, and why data are collected, and by whom, raise important questions. What governance structure is the best guide for our current public health data system? How can we ensure that new governance structures are nimble enough to address future health data considerations?[17] A strong governance structure could prevent inappropriate use of public health data, when individual users are not good stewards of the resources to which they have access. In addition, concerns that state and local preemption of federal sources of public health data with other data (or vice versa) has created misalignment and limited the acknowledgement of health and economic inequities. This tension has elevated scrutiny of the relationship between state and local governments and governance models.[18]

WHAT NEEDS TO BE DONE

SHORT-TERM

- The CDC should get input from states/localities/tribes and align goals and funding to ensure that governance and improved infrastructure robustly support local goals and needs.
- Under executive order, appoint a chief health strategist for the country.
- Establish a higher-level body that could serve advocacy and oversight functions. This body could also oversee implementation of recommendations from the Commission and other related parties.
- Set up advisory groups at multiple levels and with equitable representation to provide input on and establish a governance structure. Key decisions should seek to achieve to a more equitable balance in governance, ensure power is given to communities (including identity-based groups), and ascertain what governance looks like at each level (federal, state, local, tribal, territorial).

LONG-TERM

- Develop enforcement mechanisms to ensure sustained engagement around the principles of a transformed public health system.
- Enact statutory requirements for supporting equity in all policies.
- Generate long-term commitment from funders/investors.

WHO NEEDS TO ACT

- Federal government
- CDC
- Federal, state, local, tribal, and territorial public health leaders
- Private sector/Business leaders
- Philanthropies
- Communities/community members

Recommendation 2d. Make sharing and pooling data (at both the individual level and system level) the default for agencies receiving public money — because no one sector or institution holds all the data needed to understand the factors that drive inequities in health and well-being — and provide data to all actors.

CONTEXT. Equity in data access must ensure that the system is structured equitably so that everyone has the same level of access to the same information. Tying data expectations to federal payments is a well-established practice that could be expanded. In recent years, for example, the federal government has leveraged incentive programs to promote interoperability and the collection of a standardized set of data through the Centers for Medicare and Medicaid Services' (CMS) Meaningful Use program and, more recently, the Merit-based Incentive Payment System (MIPS). These incentive programs have tied provider payments to standards of data capture and information exchange.[19] In 2020, the Office of the National Coordinator for Health Information Technology (ONC) released the CURES Act Final Rule "designed to drive interoperability of EHI by supporting the use of ... Fast Healthcare Interoperability Resources (FHIR) standards for application programming interfaces (APIs)." [20,21] Use of FHIR, and recent federal laws, executive orders, and other federal activities fosters data sharing among a wide range of potential users, including patients, providers, and other health care entities.

> "The transformed system has to embody the ability to link data across multiple sectors and at multiple levels, from the planet to the neighborhood in order for us to understand how we got here, where we are right now, and what we are facing ahead."
>
> – Commissioner Raymond Baxter

WHAT NEEDS TO BE DONE

SHORT-TERM

- Enable linkage of data from multiple cross-sector sources with governance oversight (e.g., privacy, security, and anti-discrimination protections) that includes representatives from groups most at risk for harm from data misuse.
- Governance of data sharing should be driven at the local/state/tribal level, where the laws and the needs of the population vary dramatically, and should inform what information can be shared, with whom, and under what conditions.
- Address proprietary and other disincentives to sharing data and implement public accountability mechanisms functions where needed.
- Implement the Information Blocking Rule,22 which prohibits practices by healthcare providers and others that are likely to interfere with, prevent, or discourage data access, exchange, or use of electronic health information.[23,24]

WHO NEEDS TO ACT

- Government leaders
- State and local public health officials
- Private sector/Business leaders
- Academia/Research Institutions
- Communities/community members
- Commission members and other experts

WHAT NEEDS TO BE DONE (CONTINUED)

- Develop a federal mechanism to create interoperability standards for public health, community health, and healthcare.
- Develop a consensus statement on definitions and priorities for sharing data on measures outside public health (e.g., food security, violence, criminal justice).
- Build capacity for shared services so that communities can benefit from advances in data pooling, integration, visualization, and GIS, and build trust in sharing data.
- Involve stakeholders with appropriate expertise in training and coaching the public health workforce and supporting small public health departments through internships and skills-based volunteering to address staffing shortfalls.

LONG-TERM

- Develop a governance mechanism in consensus with relevant stakeholders and communities that addresses concerns about trust, privacy, confidentiality, and security, strengthens confidence in the process, and provides transparent choice and control.
- CMS should make conditions of participation in Medicare and Medicaid contingent on sharing data and should create a national Medicaid data set.
- Propose policy recommendations to authorize tax or other incentives for companies to offset costs and perceived disadvantages of sharing anonymized data and provide support for best practices in anonymizing data.
- Create a structure and incentives for health systems to collect critical SDOH data that follows the same equity principles suggested for government data.

> **“We need metrics that give us a pulse on what is happening in the community, as opposed to a rearview mirror look.”**
>
> – Commissioner Karen DeSalvo

Recommendation 2e. Build efficient and interoperable data systems with guidance on standardized data collection and rollup of granular categories, if needed, to generate comprehensive, complete, and timely data. Collect data with adequate granularity across population groups (inclusive of race/ethnicity, language ability, disability) and geographic levels that are useful at the community level and can be aggregated and disaggregated. Disaggregation should include multiple factors by race, ethnicity, disability, gender, and others.

CONTEXT. Public health recommendations are often made because of emerging needs, based on evolving, incomplete, and sometimes imprecise public health data. However, timely and precise (defined as exact and/or sharply defined) data are scarce, in large part because of the resources required. Ensuring an equity-oriented data system requires careful consideration about what types of data are collected and at what level of granularity, and how to balance valid concerns around individual privacy with the benefit of disaggregated data to inform public health and policy solutions. This point is particularly salient for some populations, which may be at risk if such data were made publicly available (e.g., undocumented residents, individuals with disabilities). The lack of data granularity poses challenges for understanding what works, when, and for whom, but there is no consensus on the level of geographical and other data granularity needed to support public health data decisions at the national versus local level.

WHAT NEEDS TO BE DONE

SHORT-TERM

- Convene the public and private sectors to develop a national strategic plan for data modernization, including priorities, necessary data streams, and data governance, that cuts across sectors and examines existing structures and systems.
- Investigate longitudinal health records, “data lakes” (systems or repositories of data stored in their natural or raw format), and synthetic data to refine algorithms and advance small-area estimation and the need for an opt-in or consent process for individual health records.

LONG-TERM

- Build connections to global data systems and address governance issues. Using the Health Information Technology for Economic and Clinical Health Act (HITECH) model, the CDC should contract with academic institutions through rapid grants to develop synthetic data lakes.
- Explore issues with consent for data donation to public health entities (e.g., health information exchanges, all-payer claims databases).

WHO NEEDS TO ACT

- The administration, led by the White House’s Office of Science and Technology (OSTP) in collaboration with CDC and ONC
- HHS Office for Civil Rights
- Department of Commerce
- Census Bureau
- Federal Communications Commission (FCC)
- Academia/Research institutions

Recommendation 2f. Develop agile, analytical methods to work with existing data sets and across diverse sets of quantitative and qualitative data, including integrating historical data and addressing any issues of algorithmic and related bias.

CONTEXT. Data integration across a wide range of sources, the sheer volume of health-related data, and increased computing power and technological innovation together hold great promise for the development of proactive, data-driven solutions that improve health, equity, and well-being.[25] With these changes, however, comes a need for new methodologies to analyze data efficiently, cost-effectively, and accurately.[26] To ensure that data governance and privacy protections keep pace with information technology innovation, methodologic advancements tied to tiered access and data de-identification that reduce the likelihood of re-identification could also be explored.[27] Methodologic approaches that allow disaggregation and analysis of data by geography or population characteristics could also help advance health equity.

WHAT NEEDS TO BE DONE

SHORT-TERM

- The CDC should continue to work with researchers and technology leaders to reimagine a broader methodological approach to analyzing and leveraging health data that incorporates novel methods, signals, etc., through the lens of structural and social determinants of health and health equity. This effort should focus on improving local and smaller-area data.
- Devote resources to devise better methods to pool and use existing data.
- Identify and address the bias and harm of current methodological paradigms by moving from problem-focused to solution-focused analysis. This requires guidance and protocols for understanding and using race and ethnicity as variables in health research and doing more to support research that measures the health effects of racism.[e]
- Designers of algorithms and place-based predictive metrics should assess the impact of those algorithms *across* racial/ethnic groups, and whether these metrics provide useful specificity and sensitivity and/or have limitations.
- Use novel measures that detect emergent trends or conditions, such as those surfacing on contemporary technology platforms, to capture sentiment and to track any public concerns about disinformation or misuse of data.

LONG-TERM

- Develop a code of ethics for novel measures work and other advanced methodologies and technologies, to ensure appropriate interpretation and use of the data.

WHO NEEDS TO ACT

- CDC
- Philanthropies and government to fund methodological advances
- Research methodologists (e.g., National Academies of Science, Engineering, and Medicine) and data scientists

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[e] https://www.healthaffairs.org/do/10.1377/hblog20200630.939347/full/

Recommendation 2g. Technology companies should support public health data system transformation in under-resourced areas of the country with the largest disparities in opportunities for health and health outcomes, either by direct financial support (corporate social responsibility) or through skills-based volunteer approaches.

CONTEXT. Technology companies' interest in health has continued to grow, with the expansion of smartphones, wearable devices, and application of medical devices (the Internet of Bodies). Very few data from such devices, however, are consistently used for the public good to identify emerging health needs or to inform local decision-making—partly because they tend to be about individuals rather than about populations, geographies, and societal structures and conditions, and partly because technology companies have not committed to public access. Technology companies also have a wealth of talent and are often at the cutting edge of new technologies and approaches to finding signal value (what the data are clearly showing or prioritizing) within vast amounts of data. At the same time, a larger political and societal question focuses on the role of big technology companies like Google, Facebook, Microsoft, and Twitter. The public conversations and philosophical questions about how technology companies should behave and what their role in society should be may open a new door for companies to leverage their data, resources, and expertise for public good, and to become powerful allies in crafting a modern, equity-oriented data system.

WHAT NEEDS TO BE DONE

SHORT-TERM

- Stakeholders should define roles for engaging the business community.
- Train corporate technology sector boards to improve health equity competencies, engage in discussions, support, and address what is needed for communities and different populations. Incorporate public health data sharing in Environmental, Social, Governance (ESG) standards.
- Expand broadband into rural and urban communities.

LONG-TERM

- Delineate responsibilities of technology companies to foster a national public health data strategy.
- Engage and support representation of racial, ethnic, and gender minorities and disability communities to diversify the technology field.
- Build connections with corporate responsibility and data for good programs.
- Develop strategies for under-resourced areas to gain parity with the rest of the country.

WHO NEEDS TO ACT

- Regulators
- Technology industry
- Technology stakeholders
- Other private sector/ business leaders

Recommendation 2h. Philanthropy should fund gaps in public health data, particularly for communities with fewer resources.

CONTEXT. National and regional philanthropic organizations can help catalyze a modern, equity-oriented data system. Although philanthropies cannot, and should not, underwrite the full scope of data modernization efforts, they can invest in methodologic advancements and analysis on critical issues that have blocked equity data system transformation. Through grantmaking, philanthropic organizations can help guide a national or regional agenda by addressing important gaps and needs (e.g., positive health and well-being, structural inequities). Philanthropy can also bring together diverse stakeholders to share ideas, challenge norms, and generate new solutions, and share and support the spread and uptake of evidence-based solutions using public health data.

WHAT NEEDS TO BE DONE

SHORT-TERM

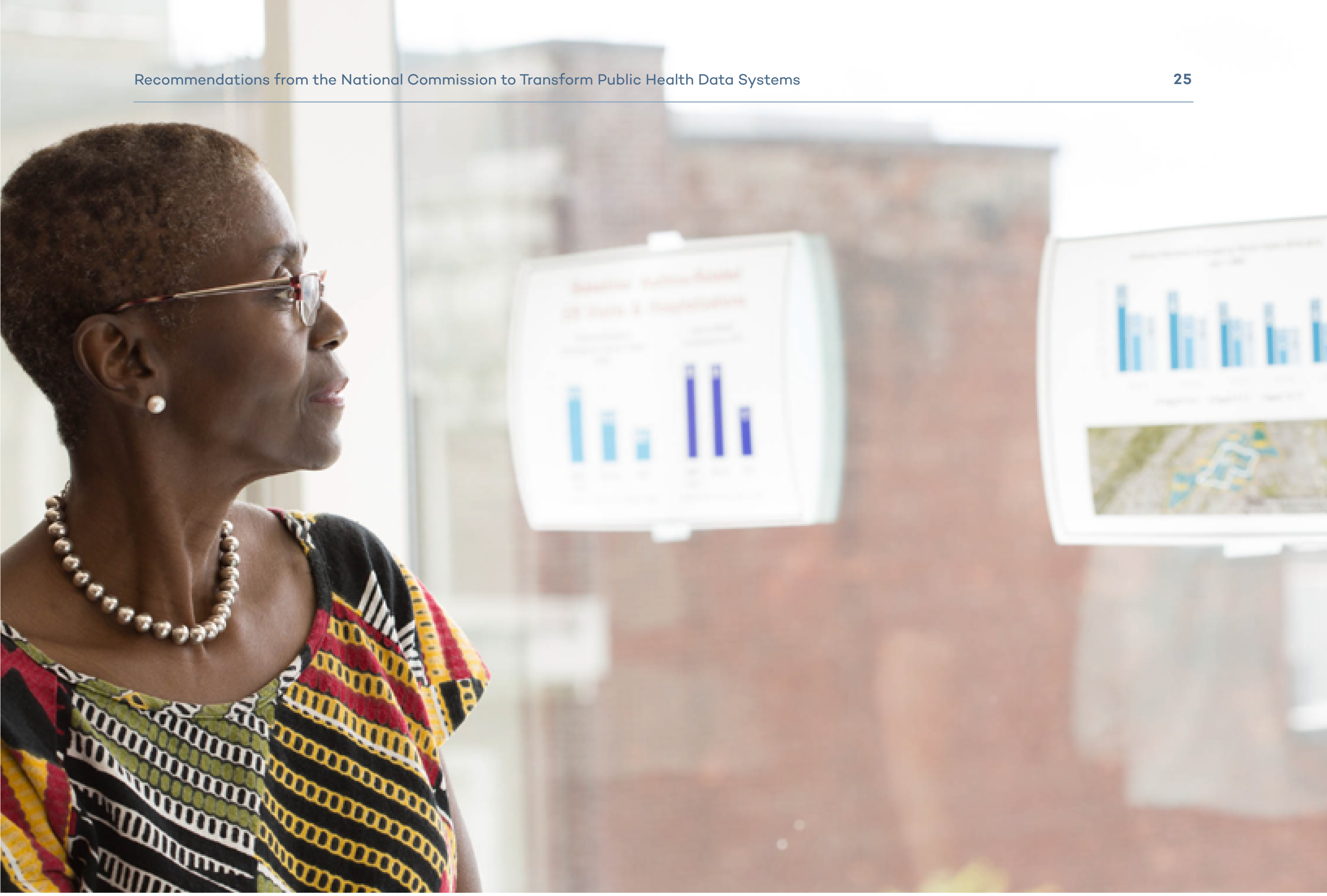
- Identify gaps in funding.
- Buy access to private data sources for communities and researchers.
- Support convening and consensus around how data on race and ethnicity and other population groups are collected, operationalized, and analyzed.

LONG-TERM

- Regional and local philanthropies should partner with national foundations to support the digital transformation of state and local public health systems. This should include improving the capacity for standards-based, bidirectional flow of data and information between public health and healthcare.
- Philanthropy should assist rural and urban providers in historically marginalized, underserved, and under-resourced communities in adopting and participating in the transformed public health data system.

WHO NEEDS TO ACT

- Philanthropies



3. Ensure Public Health Measurement Captures and Addresses Structural Racism and Other Inequities

Currently, the public health data system minimally tracks information to guide the dismantling of structural racism and address other inequities that influence health. The modern, transformed public health data system must consistently have data that measure the structural and historical factors driving persistent health inequities and that can be disaggregated and acted upon across sectors and levels of government.

> “We need better ways of capturing the concept of structural racism, but most of all we need the field to discipline itself to change the narrative of measured racial inequities to include racism and abandon reflexive pursuit of biological/genetic explanations.”
>
> – Commissioner
> Mary T. Bassett

Recommendation 3a. Build on the Executive Order (EO) on Advancing Racial Equity and Support for Underserved Communities Through the Federal Government: Equitable Data Working Group[f] to establish an interagency data council, with responsibility for equity, racial justice, and social and public health data. The interagency council would prioritize structural and systemic drivers of health and inequities, establish a process for using public health data, and create a longitudinal and sustainable program that will ensure that resources are available to maintain, improve, and periodically report on the council's progress.

CONTEXT. The COVID-19 pandemic has illuminated the need for an improved public health data system and mobilized action at the local, state, and federal levels. Coalitions and collaboratives focused on interoperability and data sharing have a renewed sense of urgency. Harnessing the collective action and power of these groups to develop a governance structure and path forward toward an equity-oriented public health data system would be a good next step. In 2007, the Agency for Healthcare Research and Quality (AHRQ) put forward the idea of a national health data stewardship entity.[28] Although AHRQ did not move forward with the idea, a convening council or other body could engage diverse sectors from social services, education, justice, the environment, along with healthcare and public health.

WHAT NEEDS TO BE DONE

SHORT-TERM

- Per the EO, establish a sustainable interagency data council, with a charge of improving measures needed to assess racial justice and bring together the different agencies with commitments to creating interoperable public health data.
- Develop standards and expectations around equity, data access, and interoperability for federal public health data.
- Include people from community-based and tribal organizations on the council and related federal agency data committees.
- Advocate for secure and efficient linkages with race and Hispanic origin data through the National Secure Data Service.

LONG-TERM

- Examine the role of technology in data interoperability and analysis, with attention to developing guidance for addressing algorithmic bias.
- Propose policies that ensure the autonomy of public health data, including related efforts, such as the Census, by placing it under bipartisan oversight. Public health relies on the Census for key measures of population health, including calculation of birth, death, and fertility rates.

WHO NEEDS TO ACT

- Office of the Vice President
- HHS, including CDC
- Office of Management and Budget (OMB)
- Congress

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f. Executive Order On Advancing Racial Equity and Support for Underserved Communities Through the Federal Government: https://www.whitehouse.gov/briefing-room/presidential-actions/2021/01/20/executive-order-advancing-racial-equity-and-support-for-underserved-communities-through-the-federal-government/

Recommendation 3b. As part of public health data system redesign, collect self-reported data by race, ethnicity, income, education, gender identity, sexual orientation, disability, and social position (i.e., how people are placed in a hierarchy of value by society, as perceived by the individual and by others). The data could be used to identify areas of disadvantage where investment and action are needed.

CONTEXT. The United States does not consistently or uniformly collect data critical to understanding the health, well-being, or lived experiences of millions of residents, severely limiting our ability to develop data-driven solutions for minority and other vulnerable populations.[29,30] Even in the midst of a worldwide pandemic, as of August 2020, data were not made publicly available and basic demographic characteristics such as race and ethnicity were not collected or were unknown for 51 percent of COVID-19 cases. These lapses masked severe inequities in case and fatality rates early on and delayed the development and implementation of data-driven solutions.[31] The lack of granularity in data and data measures impedes advancement of population health and well-being. Yet there is no consensus on the level of geographical and other data granularity needed to support public health data decisions at the national and local levels. For example, some have argued for greater granularity of ethnicity classifications to capture sub-group variations in healthcare, risk factors, and health behaviors.[32] Many data on race, ethnicity, language, sexual orientation, and gender identity originate in the healthcare delivery and financing sectors, which face barriers to data collection due to state and federal restrictions.

WHAT NEEDS TO BE DONE

SHORT-TERM

- Update and clarify the Office of Management and Budget (OMB) Standards for the Classification of Federal Data on Race and Ethnicity (Statistical Policy Directive No. 15). Consider Directive 15 a floor and encourage further data disaggregation within major race and ethnicity categories.
- Update and promulgate the recommendations of the National Academy of Medicine report on standardizing race, ethnicity, and language data.
- Assess whether local, state, and federal laws and regulations impede race, ethnicity, language, sexual orientation, and gender identity data collection and to strengthen privacy protections for those data.
- Encourage the collection of sociodemographic characteristics during all healthcare encounters in ways that preserve trust between providers and consumers.

LONG-TERM

- Include measures of structural racism as well as broader positive health metrics, such as in federal and state health-related statistical reports.
- Stratify reporting of hospital quality data by race, ethnicity, disability status, sexual orientation, and gender identity. CMS conditions of participation should address missing race/ethnicity data.

WHO NEEDS TO ACT

- National Center for Health Statistics
- CDC
- Office of Minority Health
- CMS
- National Institutes of Health (NIH)
- National Academy of Medicine (NAM)

Recommendation 3c. Invest in community-relevant and nationally significant metrics on structural factors that influence health outcomes, focusing on upstream causes of inequity by measuring how systems segregate, discriminate, and exclude.

CONTEXT. Despite increasing amounts of public health data being collected, data on the upstream factors that influence health are not regularly or consistently available to inform decision-making. A review of the Healthy People 2030 Leading Health Indicators suggests continued gaps in public health data, particularly with regard to economic stability, neighborhood and the built environment, education, and community and social context. Public health data should place more emphasis on social context and other key factors (e.g., education, housing instability, food insecurity) that have a large impact on populations with vulnerabilities and place less emphasis on traditional health data that focus primarily on disease and disease burden.[33,34] Data on lived experiences and community history (e.g., narratives), finance (e.g., mortgage acceptance rates, redlining, school budgets, county budgets, disability discrimination, language access), and racism and discrimination could provide critical insights into some of the root causes of health inequities.[35]

> “Data systems are often designed to drive interest from above and not for use by local communities.”
>
> – Commissioner Alexis C. Madrigal

WHAT NEEDS TO BE DONE

SHORT-TERM

- Identify a parsimonious (i.e., minimal and simplest) set of metrics to analyze the health effects of structural racism.
- Develop outcome measures that benchmark a newly defined set of parsimonious lead indicators of racial equity, inclusion, and well-being, and track change over time.

LONG-TERM

- Develop new measures that go beyond aggregating individual data to detect structural factors and systemic practices that separate people from health and opportunity. These metrics should provide insight on both assets and deficits that reduce and amplify separation, respectively. This requires methodologic advances to refine metrics for measuring segregation and other forms of separation (including measures of discrimination and structural racism) in institutions and systems, place-based measures that tell the full story (e.g., not masking gentrification), and a clearinghouse for best evidence. Expand frameworks for analyzing individual and community-level data in ways that support valid inferences.
- Measure upstream and downstream influences on public health, using longitudinal data to capture the history of separation and how the forces of segregation have affected people and places. Measure how policies affect systems and places, how these in turn affect people and health, and how each is impacted by interventions. Develop theoretical and empirical models to describe these processes of structural violence, acknowledging the intersectional nature of oppression in U.S society.
- Systematically measure and report racism in all its forms (internalized, interpersonal, institutional, and structural). Aggregate new or currently collected data, including self-reported experience with racism, measurement of discrimination, housing discrimination, and other measures like school exclusionary discipline and gun violence.[g]
- Incorporate these measures into value-based alternative payment models in Medicare, Medicaid, and private insurance plans.
- Create written guidance on interpretation of racial/ethnic health disparities that recognizes “racism as the mechanism by which racial categorizations have biological consequences.”[36]
- Develop guidelines to support improved measurement and analysis of structural drivers of health inequities in community health needs assessments by not-for-profit hospitals and public health departments, as well as community development financial institutions.

WHO NEEDS TO ACT

- OMB
- AHRQ
- Congress
- Academia/Research institutions

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[g] Bi-annual AHRQ report: https://www.ahrq.gov/workingforquality/reports/index.html

Recommendation 3d. Collect accurate, relevant community-level data that support small-area estimates so that communities and local health departments can better prioritize and address local health challenges and measure progress toward healthier communities.

Context. The public health data system must have both flexibility and interoperability; it must allow for local flexibility while ensuring that data collected locally can be easily combined with data collected elsewhere. Modularity connotes "the degree to which a system's components can be separated and recombined and refers to ... the degree to which the rules of the system architecture enable or prohibit the mixing or matching of components."[37] In contrast, systems consolidation or integration is another approach to ensuring interoperability, but it is less flexible in meeting emerging or unique needs. Standardized measures would not only support interoperability but would also allow stakeholders to select those measures most relevant to their work, greatly increasing the flexibility of the public health data system.[38]

> "An equity-focused data system will not just describe problems; it will help us work towards solutions. It will be a valuable tool for social justice."
>
> – Commissioner Fernando De Maio

WHAT NEEDS TO BE DONE

SHORT-TERM

- Guide local leaders in identifying parochial public health measures and data priorities, with consideration of uniformity to support analysis and interoperability over time, including interoperability at intra-local levels, which can be rolled up optimally to the state level.

LONG-TERM

- Provide supports to a local data workforce that can tailor data collection efforts locally and employ small-area estimations and other techniques.
- Ensure that the National Secure Data Service can support small-area estimation needs through access to administrative data that lend strength to local data to produce statistics.

WHO NEEDS TO ACT

- Census Bureau
- National Center for Health Statistics
- NIH
- Department of Housing and Urban Development
- Departments of Education and Public Health
- Department of Agriculture
- Department of Commerce
- Parallel agencies at state and local levels
- Municipal and county planning agencies
- Academia/Research institutions

Recommendation 3e. Develop methods for interpreting public health data that include community input, paying attention to messaging, communication, and narrative. Advance training for the workforce, the public, and communities to use and interpret data.

Context. Representation and power in health decision-making are integral to a modern, equity-oriented public health data system. Power[39] means the authority to shape expectations, decisions, and outcomes in public health. The current public health data system does not prioritize transparency, data access, and use that support sustained civic engagement. Nor does it give deep consideration to the voices of historically marginalized and chronically underrepresented populations, which are required for truth, reconciliation, and racial healing. This focus on equity in data use and decision-making is even more critical in the context of the greater volume, velocity, and variety of data (often used to characterize "big data"), the role of technology in data generation and manipulation (e.g., artificial intelligence, machine learning), and increasing challenges to civic engagement and democracy.

WHAT NEEDS TO BE DONE

SHORT-TERM

- Establish a community advisory council (via the federal advisory committee process) to provide guidance on public health data sources, uses, and interpretation of data and ensure genuine community engagement.
- Work with higher education to develop public health data analytic methods that are interdisciplinary, action oriented, data driven, and aligned with the revised 10 essential public health services.

LONG-TERM

- HHS should provide resources to states, tribes, local health departments, and coalitions to develop best practices for bringing community voice to governance, collection, use case prioritization, and interpretation of data and outcome measures.
- Use a Community Commons (a method of creating a network of changemakers focused on health, equity, and sustainability) model as a data repository to help communities engage with and promote data that are compelling, advance a public health narrative, support action, and demonstrate that health equity can be improved.

WHO NEEDS TO ACT

- HHS
- State and local health departments
- State, regional, county, and municipal planning agencies
- Academia/Research institutions

COMMISSION FORMATION AND DELIBERATIVE PROCESS

Why this Commission Now?

RWJF's Transforming Public Health Data Systems to Advance Health Equity (TPHD) initiative supports efforts to reimagine the nation's public health data system to address structural racism and advance health equity. The COVID-19 pandemic has affected communities unevenly across the country, disproportionately burdening people of color in regions, cities, and neighborhoods that have been historically underserved and under-resourced. We know that only by patching together uncoordinated data collection efforts—from local health departments, academic sources, and a host of nontraditional actors—that used different data sources, such as private technology firms, journalist networks, and public intellectuals who have leveraged social media.

For years, a mix of underfunding, complicated governance structures, and technological limitations has plagued these disparate data systems. As a result, their response to COVID-19 was often slow, of varying quality, and unable to answer key questions from public health leaders, policymakers, and the general public. Their failures revealed systemic dysfunction that requires attention, but they also laid bare the impact of structural racism on our capacity to leverage data to improve health. Data have not been consistently collected by race and other demographic characteristics, a reflection of how Black and Brown lives have been undervalued in America. Further, when disaggregated data have been available, they have been interpreted with insufficient contextualization,[40] perpetuating myths and further stigmatizing Black people and communities.

When COVID-19 hit, RWJF launched Transforming Public Health Data Systems to catalyze development of a better public health data infrastructure that would be prepared for the next pandemic and to tackle ongoing public health challenges. While the nation's current public health data system generally falls short, the COVID-19 pandemic has starkly revealed its failings when it comes to protecting the most vulnerable. For a Culture of Health to truly exist, we need a public health data system that is reliable and effective. And for health equity to advance, we need one that centers populations that historically have been afterthoughts in the conceptualization and design of systems for data collection, sharing, linking, and analysis.

The TPHD Commission was formed in 2020 to review the most significant challenges to the nation's public health data system and provide recommendations to policymakers, healthcare organizations and institutions, service providers, and philanthropy on how to initiate solutions.

Preparation

Commission deliberations were informed by four complementary activities conducted between October 2020 and April 2021. These components included an environmental scan of literature, reports, coordinated activities, emerging policies, and executive orders related to data modernization and public health data system transformation; and interviews with over 100 individuals selected for their expertise and thought leadership on the main topics to be addressed by the Commission. RAND conducted both efforts between October 2020 and February 2021.

At the same time, RWJF asked a set of research teams (grantees) to conduct targeted studies to deepen understanding of public health data system issues, surface promising practices and case examples of innovation in public health data development and use, and identify systemic changes to facilitate a modern, equity-oriented public health data system. The grantees are continuing their efforts through 2021, but the Commission drew on early insights from their work, as of April 2021. RAND incorporated these insights incorporated into its white papers, which also included findings from the environmental scan and interviews.

The fourth component involved focused discussions with five expert panels on population-specific data gaps (American Indians/Alaska Natives, Blacks/African Americans, LGBTQ+ communities, people living with disabilities, and women), offering additional insight and context specific to the experiences of these populations. These findings from the expert panels were summarized along with the white papers to inform Commission deliberations.

Each of these components is described in more detail below.

Four Components of Formative Work

ENVIRONMENTAL SCAN

RAND conducted an environmental scan to identify key issues, points of consideration, tradeoffs and tensions, and current activities related to public health data, data systems, and data modernization efforts. This effort included a targeted scan of published research papers and reports, reviews of websites and working documents describing coordinated activities (e.g., data interoperability), and recent initiatives. It also included a review of federal executive orders, emerging policies, and funding opportunities relevant to public health data systems and health equity, as of June 2021.

The environmental scan initially covered five broad topics: (1) what is public health and public health data, (2) data disaggregation and implications for equity, (3) stewardship and governance of data, (4) private sector innovations in public health data collection and use, and (5) data interoperability. Additional searches included the use of "big data" in public health, data privacy, and ethics of public health data collection. For each topic, the team primarily focused on public health data, but also identified seminal articles and reports from other sectors or disciplines whose findings could apply to public health data systems. For seminal articles, the team reviewed references and pulled additional articles and reports for inclusion in the white papers.

EXPERT INTERVIEWS

RAND conducted semi-structured interviews with 112 experts and thought leaders on the main topics before the Commission. Individuals represented diverse sectors, including public health and healthcare, technology and data science, research and policy, journalism, and law. The interviews also included experts in data, data use, equity, community engagement, and research translation who work *outside* the traditional health sector but in areas germane to the social determinants of health (e.g., environment, community development).

Interviews were designed to elicit insights and perspectives in the following domains, which aligned with the environmental scan. Issues of equity were probed within and across all domains.

- Vision for public health data and gaps and challenges in current public health data, including social determinants of health
- Content and types of public health data
- Data disaggregation and implications for equity
- Access to and use of public health data
- Public health data governance and stewardship
- Role of data providers (public and private sector) and users
- Operational elements of public health data (e.g., features of interoperability, legal issues, privacy)

RWJF GRANTEES

Eighteen research teams received grants from RWJF to deepen understanding of public health data system issues and to highlight promising practices and case examples of innovation in public health data systems. Grantee selection was separate from the environmental scan. These in-depth looks are briefly summarized in Table 1 by grant title and theme area. As noted, the grantees are continuing their efforts through 2021. Early insights from each grantee's work, emerging as of April 2021, were incorporated into white papers developed for the Commission.

The projects may be grouped generally by the themes noted above. Although the grouping below is organized by a primary theme, most grantee work crossed multiple themes and informed the development of the white papers and Commission deliberations broadly.

TABLE 1. TARGETED STUDIES ORGANIZED BY BROAD THEME AREAS

Vision for public health data as well as gaps and challenges in current public health data	
National Foundation for the Centers for Disease Control and Prevention, Inc.	Facilitating transforming public health data systems at the U.S. Centers for Disease Control and Prevention to advance health equity in a time of pandemic
Task Force for Global Health, Inc. (Public Health Informatics Institute)	Accelerating efforts in a time of pandemic to modernize the U.S. public health system's approach to disease surveillance
Content and types of public health data	
New York University	Reporting on "third generation" sources of public health surveillance data to guide public health practice during and beyond the pandemic
United Way Worldwide	Assessing the value, best practices, and potential uses of 211 data to inform public health during the pandemic and beyond
Data disaggregation and implications for equity	
Croal Services Group, LLC	Identifying systems-level barriers to complying with and expanding national race/ethnicity data disaggregation standards
Urban Institute	Conducting research during a pandemic to document best practices for appending race and ethnicity to data sources lacking that information
Texas Southern University Foundation	Strengthening health equity data gathering to better understand the genesis and impact of health disparities, especially during a pandemic
Drexel University	Tracking equity issues in COVID-19 testing and vaccination access in selected cities
University of North Carolina at Chapel Hill	Expanding data collection under the COVID-19 Prison Project to help transform public health data systems and advance health equity
University of California, Los Angeles	Creating a model for data-driven policymaking for Native Hawaiian and Pacific Islander populations in time of pandemic to help promote health equity
Access to and use of public health data	
INFO LINE of San Diego County dba 2-1-1 San Diego	Leveraging community information exchanges for equitable and inclusive public health data systems during a time of pandemic
Health Care Cost Institute, Inc.	Assessing the feasibility of developing a permanent platform for making private data available to researchers for noncommercial use
Role of data providers (public and private sector) and users	
National League of Cities Institute, Inc.	Building a citywide coalition committed to using well-being data to advance health equity during a pandemic
Community Science, Inc.	Understanding the strengths and weaknesses of mutual aid and grassroots organizations to effectively respond to challenges and crises
Rush University Medical Center	Supporting Rush University Medical Center in improving the use of preventive services by democratizing data during a pandemic
Operational elements of public health data (interoperability, legal issues, privacy, ethics)	
Project Evident, a project of the Tides Center	Studying data interoperability across sectors and developing a shared understanding of "health data" to drive community change during a pandemic
University of Arkansas for Medical Sciences	Analyzing barriers to sharing data across criminal justice settings and with health settings to advance health outcomes and equity
Third Sector New England/Network for Public Health Law	Ascertaining the role of law in public health practice to facilitate use of disaggregated data to advance racial/ethnic equity during a pandemic

The targeted studies by RWJF grantees surfaced critical issues that the Commission explored further. These topics included the timeliness, quality, and content of data; how data are disaggregated, shared across sectors and organizations, and represented; how community leadership is included in local data decision-making; and how data are translated and used for public health policy.

POPULATION-SPECIFIC EXPERT PANELS

The Commission's formative work included focused discussions with five expert panels on population-specific data gaps (American Indians/Alaska Natives, Blacks/African Americans, LGBTQ+ communities, people living with disabilities, and women). Each panel consisted of individuals who brought expertise to the issues based both on their work and training with data and their own lived experience. Having the expertise and voices from those communities was critical to shaping recommended strategies and approaches to advance data systems and data equity. Each panel convened virtually for eight hours over three days. In addition to panel-specific findings summarized here, all panels highlighted the importance of narrative change around health, well-being, and equity; the need to decolonize and disaggregate data; the importance of authentic community engagement in data decision-making; the importance of training and capacity-building around data; and the need to overlap intersectional identities and experiences in more comprehensive data systems.

Synthesis of Formative Methods to Guide Commission

Collectively, findings from these four methodological approaches were synthesized and provided to the Commission in advance of its deliberations. The Commission ultimately had many resources upon which to draw for its work: the series of white papers developed by RAND reflecting the environmental scan, expert interviews, and areas of targeted study; the insights obtained from the expert panels; any additional findings from grantees available at the time of Commission deliberations; and other resources as part of Commission deliberations (described in the next section).

This methodological approach afforded the Commission the depth of multiple perspectives and research streams to inform its recommendations around the need for narrative and structural changes in a modern and transformed public health data system. As noted in the following section, this formative work, combined with deep meeting dialogue and deliberations, distinguished the ultimate Commission recommendations by ensuring that recommended structural changes for the future public health data system are centered on equity, lived experience, and the root drivers of health outcomes.

Selection of Commission Members and Deliberation Process

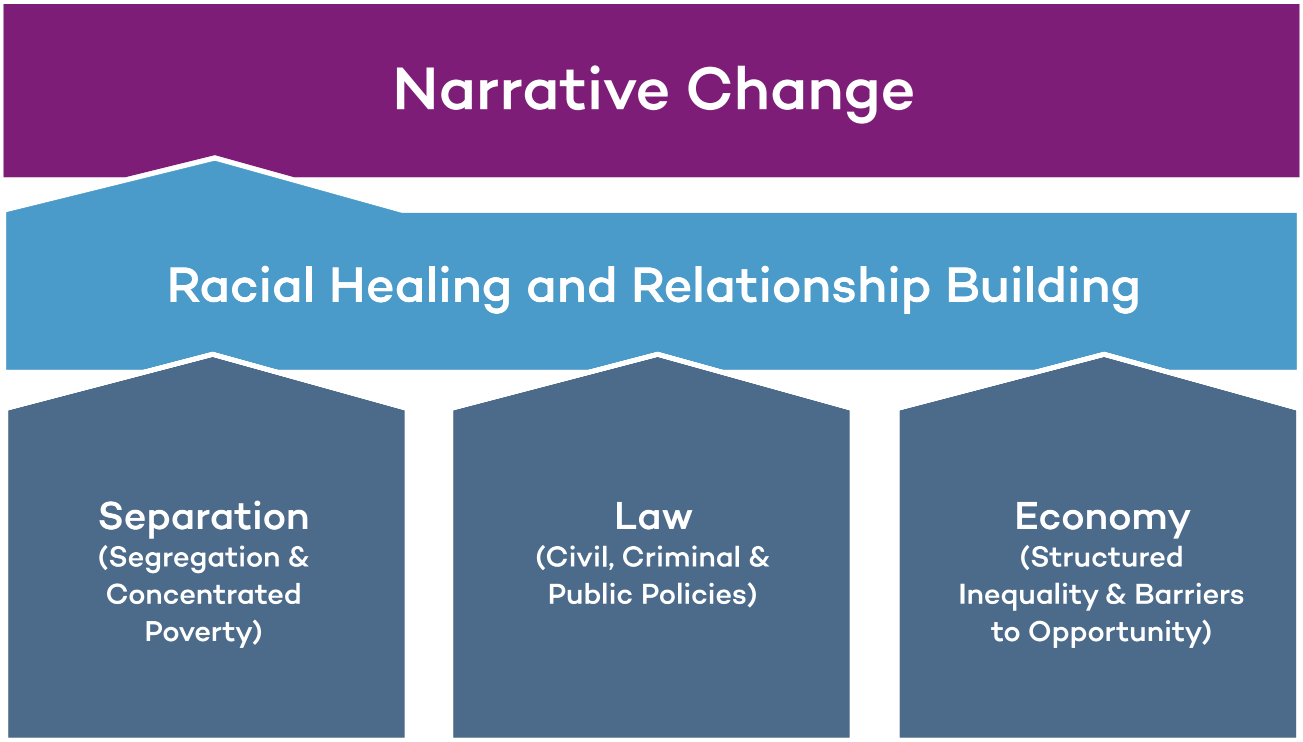
The Transforming Public Health Data Systems Commission process extended over approximately one year and involved several phases leading up to and including the production of the final report. As mentioned, the process began with research and field-scanning work and a portfolio of innovative, action-focused "quick strike" RWJF grants. These Foundation investments provided a set of background reports, level-setting documents, and resources to inform the Commission's deliberations. These resources also informed the selection process for Commission members.

The process of outreach, vetting, and selection was designed to include diverse scholars, innovators, public health leaders, and activists from across the country. All these phases occurred during the COVID-19 pandemic, which, understandably, constrained the flexibility of some local and national leaders to participate. That said, the resulting panel of Commission members was representative of the field of public health data research and management, as well as diverse demographics, sectors, and issues.

Given the expressed equity intention of the charge and the urgency created by the pandemic, racial reckoning momentum, and economic upheavals in 2020, the Commission adapted the nationally recognized Truth Racial Healing and Transformation (TRHT) Framework and engagement steps for its deliberations. TRHT is an adaptation to the U.S. context of the globally recognized Truth and Reconciliation (TRC) process, whose most recognized application was in South Africa. Envisioned by Gail C. Christopher and launched in 2016 by the W. K. Kellogg Foundation in collaboration with several other philanthropies, TRHT is now used by thousands in colleges and universities, nonprofits, government, and private entities around the United States. This framework has five pillars:

- Narrative Change
- Racial Healing and Relationship Building
- Separation
- Law
- Economy

FIGURE 1. TRHT FRAMEWORK



These pillars reflect the comprehensive, coordinated work and strategies required for collective movement toward a more racially just and equitable society. Our stories about who we are as a country and how we became America must be revisited and revised to reflect more authentic, expansive, and inclusive voices of diverse groups. At the same time, we must build individual and collective capacities and tools for relating across perceived barriers and entrenched lines of difference. This requires relational skills and competencies associated with racial healing and cross-identity group communication.

These processes of changing racial hierarchy narratives and expanding circles of engagement for equity and justice enable the work on the remaining pillars of the TRHT Framework: Separation, Law, and Economy. These three words embody the primary systemic and structural tools and means used to create and sustain systems of exclusion, oppression, and racial hierarchy based on the belief in a hierarchy of human value. Now that racism has been declared a "public health crisis" by more than 200 local health jurisdictions and, most recently, by the CDC, it is time to transform public health data systems into engines that can help drive the healing and transformation of our democracy from its centuries-old roots in racial hierarchy toward its aspirational tenets of equal human rights and fairness for all.

The TRHT Framework requires five sequential steps. The first is visioning and reimagining the successfully changed future. This is done for each house pillar. Once the future state is agreed upon, participants analyze the current landscape or "now" in light of this vision. This step is followed by identifying resources, human and financial, needed to achieve the vision. Finally, participants develop short-term and long-term recommendations for specific actions by designated institutions, sectors, or groups. Members of the TPHD Commission, together and in teams representing the five pillars, undertook this process.

Charged with reimagining the nation's public health data system to address structural racism and advance health equity, the Commission was convened virtually and engaged in a participatory deliberation process designed and facilitated by the National Collaborative for Health Equity (NCHE) team. Teams aligned with the five TRHT pillars discussed their visions, deliberated priorities, and shaped recommendations collaboratively. Ultimately, the visioning and recommendations from the five TRHT Framework pillars were adapted and condensed into three focus areas for public health data and data systems transformation efforts, reflecting the vision statements developed by the Commission teams as they deliberated.

The first theme, **Health Equity and Well-Being in Narrative Change**, was reflected in vision statements calling for sustainable and transparent data collection conducted in collaboration with communities and people most impacted by social and economic disparities to build trust and provide the contextual and historical data needed to change the narrative, disrupt the status quo, and enable restorative and prospective storytelling.

The second theme, **Equitable Governance, Systems, and Community Engagement**, emerges from vision statements related to building an agile, well-resourced public health data system that respects communities' agency in understanding and governing themselves and has a high degree of interoperability, allowing for stakeholder engagement and interaction. The transformed public health data system would take a broad view of both the processes and outcomes of health and well-being, encompass different domains of life (e.g., health, economy, social, cultural, environmental) across systems and institutions (e.g., education, housing, labor, development, health care, criminal justice, immigration); measure both harmful exposures and positive assets/strengths/opportunities of communities, places, and experiences; and account for upstream macrostructural factors (policies, practices, and systems).

The **Measuring and Addressing the Health Impact of Structural Racism and Other Inequities** theme reflects vision statements about the need for a public health data system that characterizes separation, segregation, and barriers to opportunities in

measurable ways, and addresses the problems of missing data and misuse of data. The data system would set new targets and measure progress toward those targets, addressing needs for storytelling, data analytics, policy development and evaluation, and programmatic use. It would monitor wellness for the whole person and the whole community and help determine what works and what does not.

Conclusion

Time and again, major crises such as global pandemics precipitate meaningful and constructive societal change. Sewer systems, public parks, and clean water systems are a few examples of major innovations that transformed cities and society following pandemics. It seems fitting that, in this information era, the COVID-19 pandemic will generate innovation and transformation in how public health data are collected and leveraged to foster better health and well-being for all.

We hope that the recommendations in this report will help transform understanding of public health data and how they can be applied to advance health equity and racial justice. COVID-19 revealed stark and painful racial inequities in the determinants of health and opportunities for well-being. In so doing, this pandemic and its attendant racial reckoning and economic crises must compel actions by and across all sectors to address and redress historic and contemporary patterns of inequitable access to opportunity. COVID-19 demonstrated the shared costs of inequality. We now have greater insight into the role of accurate, timely, accessible, and comprehensive public health data in driving decisions for needed investments to produce better and more equitable outcomes—whether it's access to safe, affordable, stable housing or transportation to and from vaccination centers.

Public health data can be used to create unprecedented systems of accountability for progress toward greater fairness and equity. The recommendations in this report aim to engage and catalyze representatives from local communities, nonprofit organizations, and academia, as well as from private, public, and philanthropic sectors. It is a report for and call to action to the nation about how we must collaborate, expand, and innovate to measure and invest in the health and well-being of all populations.

CALL TO ACTION

COVID-19 and the national reckoning with racism and other social inequities have activated a long overdue national health consciousness. Critical to the success of the modern public health data system is a focus on equity in the story, content, and structure of public health data; how those data are used to address the painful toll of racism and other systemic inequities; and the engagement of diverse stakeholders in access to and use of data for decision-making—all with attention to issues of power, marginalization, and justice. Now is the time for the public health field to crystallize a "moonshot" or a more ambitious north star to chart a clear path to health, well-being, and equity that enables everyone to live their healthiest life and thrive. This shared vision can help sectors and stakeholders accelerate action, commit to transforming the public health data system through their own work, and join forces to amplify impact. This section outlines the ongoing actions that should be pursued by government as well as private and other civil society sectors to transform our public health data system.

Government

Federal, state, and local government leaders can support critical public health data infrastructure, clarify the need for consistency in public health data (e.g., how subgroups are captured), and affirm how data can help address structural racism and other inequities. Here are examples by level of government:

FEDERAL GOVERNMENT

- Develop minimum standards for data collection, disaggregation, presentation, and access in federally funded data collection efforts, with an orientation to "freeing federal data" or promoting greater access. Standards should include how to balance privacy considerations, the importance of subgroup analyses, the critical application of relevant tribal policies in data review, how the impact of racism is measured, and federal workforce training in public health data.
- Strengthen public health data infrastructure and incentivize the use of new data collection and analytic approaches through a public messaging campaign and a combination of policies, funding mechanisms and priorities, and guidance to state and local agencies.
- Restrict federal funding for data infrastructure to systems that are standards-based and interoperable.
- Offer guidance on interpretation of racial/ethnic variation in health-relevant data to counter longstanding acceptance of the idea that these variations reflect biological differences rather than systemic, cultural, behavioral, and social factors.

STATE GOVERNMENT

- Ensure that state policies for public health data collection, sharing (including balancing privacy and transparency), and analysis are equity driven and explicitly call out the influence and consequences of structural racism and other inequities on health.
- Partner with local health departments and departments that provide public health data (e.g., social services data) to consider new models of collaboration to improve efficiency and timeliness of decision-making and action at state and local levels.

LOCAL GOVERNMENT

- Regularly connect public health data to local communications (i.e., what is happening in the community and how it relates to overall community well-being, or the impact of inequity).
- Ensure that local voice is represented not only in public health data (e.g., from whom data are collected), but in those positions of authority responsible for making sense of the data and informing decisions.
- Explore data-sharing collaborations across government and civil society (e.g., nonprofits, businesses) that can more consistently generate public health data to support equity considerations and advance innovative public-private collaborations on data and analysis.

Public Health

Eroding public trust and sustained disinvestments in public health have produced significant variability in capacity and infrastructure to collect, analyze, share, and leverage existing data to identify and address emerging health concerns and structural inequities that affect health.

- Lead multisector collaboration around public health data sharing to improve the timeliness and quality of data to strengthen local decision-making.
- Strengthen capacity, diversity, and ongoing training of the public health workforce to monitor and address health equity, both in the field of public health and through novel collaborations with business, academia, or other sectors that influence health.
- Advocate for and prioritize modernization efforts and data sharing within and across the public health system to ensure that local data can inform emerging public health concerns at the regional, state, and national levels in real time.

Businesses

Businesses generate and analyze health data. Very few of these data, however, are consistently used for the public good to identify emerging health needs or to inform local decision-making.

- Work with government partners and other organizations to develop standards through which public health data generated by the private sector can be used and communicated.
- Engage in more consistent workforce exchanges and data partnerships with public health organizations to cross-pollinate innovations in the types, content, quality, and precision of public health data.
- Foster public health innovation by promoting methods in use by technology companies, such as data integration, “big data” analytics, and data security.

Healthcare Systems

Healthcare systems have increased the collection of data on SDOH and other “non-clinical” factors that influence health (e.g., isolation, lack of social support), primarily at the individual level.

- Consistently collect SDOH data during consumer encounters, using standardized questions and ICD-10 codes that allow data aggregation within communities.
- Connect these data on individual social needs (e.g., housing), with structural inequities confronted by consumers (e.g., neighborhood characteristics, trauma exposure, experiences of discriminatory policies) to offer useable information on equity to the community.
- Overcome historic silos and build partnerships and legal solutions to facilitate sharing of relevant healthcare data with public health departments in a timely and efficient manner, allowing data linkages and disaggregation of subgroups and geographic regions.

Nonprofits, Professional Associations, and Schools

Nonprofits and community-based organizations are foundational to understanding existing and emerging health needs of the community. Professional associations, including the Association of State and Territorial Health Officials and the National Association of County and City Health Officials, and research institutions like the National Academies of Sciences, Engineering and Medicine are trusted organizations and often the go-to places for information and resources for their members. Schools of public health are developing the future workforce for the modern public health data system.

NONPROFITS

- Build trust in data as a public good in the community and among constituents, identifying relevant issues (e.g., around privacy or how data will be used). Support the development of solutions that address concerns to ensure that such data do not further marginalize or bring harm to populations.
- Work locally to develop data-sharing strategies with government, and, where appropriate and where there is health benefit, reciprocity, and equitable access.

PROFESSIONAL ASSOCIATIONS

- Develop strategies to improve data completeness and quality, particularly with respect to equity and drivers of health and well-being.
- Actively work with professional associations from other sectors that influence health (e.g., education, social services, environment) to align efforts, particularly around standardization and data use. This can minimize variability across sectors that impedes effective data sharing and understanding around health trends at a local level.

SCHOOLS

- Help students monitor and evaluate structural and systemic inequities and understand what data systems must include to call out those inequities.
- Train the next generation of public health practitioners and researchers to meaningfully partner with local stakeholders and to value lived experience and community expertise as much as formal training.

PHILANTHROPY

Philanthropic organizations can guide an agenda by calling out important data gaps (e.g., positive health and well-being, structural inequity data), and offer strategic and catalytic investments to support methodologic advancements and generate new solutions.

- Promote a national, unifying health goal that can be understood and executed, with a focus on the role of structural racism and the values of health equity and well-being.
- Leverage convening and funding opportunities to meaningfully engage leaders, including those from non-health sectors and community organizations, who can advance the importance of public health data.
- Focus funding on key parts of data systems modernization, such as improving governance and using new forms of data and analytic methods to convey better stories of health equity and well-being.

ACKNOWLEDGEMENTS

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GLOSSARY

CONFIDENTIALITY. The obligations of individuals or groups that receive or use information to respect the privacy interests of individuals who are subjects of the data.

DATA DISAGGREGATION. The collection, provision, and reporting of data by subcategories.

DATA EQUITY. The collection, provision, and reporting of demographic data that consider the equity consequences and sociopolitical nature of the category definitions.

EQUITY. Defined in shorthand as the fair and just access to opportunity. There are many types of equity, such as:

- ***Distributive equity*** focuses on allocation and resource management decisions, with attention to the balance of costs, risks, and benefits. Usually, distributive equity considers how decisions are made and benefits are distributed based on dimensions of need and social benefit.
- ***Procedural equity*** addresses how the concept of fairness is included in approaches and policies once the equity parameters are set (i.e., for whom are we improving equity).
- ***Contextual equity*** is the backdrop for both procedural and distributive equity, accounting for the political, economic, social, and intergenerational factors that influence how populations engage with society and its systems and benefits. This includes contextual variables such as access (e.g., access to capital) and power (e.g., the ability to gain and maintain access to resources).

EQUITY-ORIENTED. A public health data system that centers equity, or the fair and just access to the opportunity to be healthy, in the content and structure of data; the engagement of diverse stakeholders in the access to and use of data for decision-making, with attention to issues of power, marginalization, and justice, and in how data are used to address systemic inequities.

HEALTH EQUITY. Everyone has a fair and just opportunity to be as healthy as possible. This requires removing obstacles to health such as poverty, discrimination and its consequences, powerlessness, as well as lack of access to good jobs with fair pay, quality education and housing, safe environments, and health care (Braveman, 2017).

HEALTH INEQUITIES. Systematic differences in the opportunities that groups have to achieve optimal health, leading to unfair and avoidable differences in health outcomes. The dimensions of social identity and location that organize or “structure” differential access to opportunities for health include race and ethnicity, gender, employment and socioeconomic status, disability and immigration status, geography, and more.

INTEROPERABILITY. The ability of systems that create, exchange, and consume data to have clear, shared expectations for the contents, context, and meaning of those data, ensuring that information is shared appropriately among systems and partners in the right format, through the right channel, and at the right time (www.cdc.gov and Data Interoperability Standards Commission).

GOVERNANCE. The structures and processes by which people in societies make decisions and share power, creating the conditions for ordered rules and collective action. Data governance refers to how data are structured, shared, and protected.

MACHINE LEARNING. The use of computer systems to learn and adapt by using algorithms and other models to analyze and draw inferences from data patterns.

NARRATIVE. Narratives shape the way people see and think about the world around them. They are expressed, received, and internalized through stories and experiences in art, popular culture, traditions and common practices, the built environment, policies, systems, and structures, and more. Aggregated over time—and filtered through lived experience, culture and environment, and the echo chambers where people seek feedback and validation—narratives influence the way people make sense of their surroundings, interpret information, and make decisions. (See metgroup.com/narratives for more information.)

PARTICIPATION. The active role of those impacted by public health decisions in the process of arraying decision options and providing meaningful input on those decisions.

POWER. The authority to shape expectations, decisions, and outcomes in public health.

PRIVACY. An individual's rights to control the acquisition, uses, or disclosures of his/her/their identifiable health and other data.

PUBLIC HEALTH DATA SYSTEM. The Commission defines a modern, transformed public health data system as one that is accountable to and reflects the perspectives of local communities and diverse populations, including people of color, immigrants, persons with disabilities, and the LGBTQ+ community. The system must be sustainable, fully integrated with healthcare and other sectors that drive health by linking data across multiple sectors and at multiple levels, and provide data that are disaggregated, comprehensive, and timely. It should move from problem-focused to solution-focused research and have the capacity to provide the knowledge needed to optimize health and well-being for all people. It must provide tools to address racism and racial/ethnic and other social disparities; it should facilitate restorative systems that respect all communities, including the sovereign right of tribal nations to govern data and ensure they have access to them; protect individuals' privacy and security; and guard against unintended consequences.

SECURITY. The technological or administrative safeguards or tools designed to protect identifiable health data from unwarranted access or disclosure.

SENSEMAKING. The cognitive processes by which people make meaning from data and experiences.

SMALL AREA ESTIMATES. Using statistical techniques to develop estimations of small sub-populations.

STRUCTURAL RACISM. The laws, policies, cultural representations, and norms across interconnected systems that support the unfair treatment of some groups based on the social construct of race that is grounded in a false ideology of a hierarchy of human value.

SYNTHETIC DATA. Information that is artificially generated rather than produced from actual events.

VOICE. The inclusion of the perspectives, ideas, and lived experiences of those impacted by public health decisions.

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RESOURCES

Business Case for Racial Equity

https://www.wkkf.org/resource-directory/resources/2018/07/business-case-for-racial-equity

Closing the Racial Inequality Gaps: The Economic Cost of Black Inequality in the U.S.

https://ir.citi.com/%2FPRxPvgNWu319AU1ajGf%2BsKbjJjBJSaTOSdw2DF4xynPwFB8a2jV1FaA3Idy7vY59bOtN2lxVQM%3D

Commission on Security and Cooperation in Europe (Helsinki Commission), Briefing on Truth, Reconciliation, & Healing: Toward a Unified Future

https://www.csce.gov/sites/helsinkicommission.house.gov/files/FINAL.Christopher%20Written%20Testimony%20Helsinki%20Jul2019%20%281%29-converted.pdf

Deconstructing Inequities — Transparent Values in Measurement and Analytic Choices

https://www.nejm.org/doi/full/10.1056/NEJMms2035717

Ethics and Empathy in Using Imputation to Disaggregate Data for Racial Equity: Recommendations and Standards Guide

https://www.urban.org/research/publication/ethics-and-empathy-using-imputation-disaggregate-data-racial-equity-recommendations-and-standards-guide

The HOPE Initiative: Measures to Advance Health and Opportunity

https://www.hopeinitiative.org/

Including disability in all health equity efforts: an urgent call to action

https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(21)00115-8/fulltext

Physician–patient racial concordance and disparities in birthing mortality for newborns

https://pubmed.ncbi.nlm.nih.gov/32817561/

Racism and Health: Evidence and Needed Research

https://pubmed.ncbi.nlm.nih.gov/30601726/

The Impact of Chronic Underfunding on America's Public Health System: Trends, Risks, and Recommendations

https://www.tfah.org/report-details/pandemic-proved-underinvesting-in-public-health-lives-livelihoods-risk/

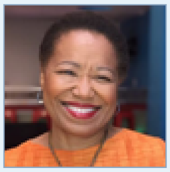
Truth, Racial Healing, and Transformation: Creating Public Sentiment

https://www.nationalcivicleague.org/ncr-articles/truth-racial-healing-transformation-creating-public-sentiment/

Understanding Hate Through a Public Health Lens

https://preventioncentre.org.au/resources/understanding-hate-through-a-public-health-lens/

MEET THE COMMISSIONERS



GAIL C. CHRISTOPHER, DN, is the director of the National Commission to Transform Public Health Data Systems and serves as executive director of the National Collaborative for Health Equity. She is also a senior scholar at George Mason University's Center for the Advancement of Well-Being. Christopher is an award-winning social change agent with expertise in the social determinants of health and well-being and in related public policies. She is known for her pioneering work to infuse holistic health and diversity concepts into public sector programs and policy discourse. In her role as the senior advisor and vice president at the W.K. Kellogg Foundation (WKKF), she was the driving force behind the America Healing initiative and the Truth, Racial Healing and Transformation effort. Christopher also served as WKKF's vice president for programs. In 2015, she received the Terrance Keenan Award from Grantmakers in Health. She chairs the Board of the Trust for America's Health. She is the visionary for and architect of the WKKF-led Truth Racial Healing and Transformation (TRHT) effort for America. TRHT is an adaptation of the globally recognized Truth and Reconciliation Commission (TRC) model.

MARGARITA ALEGRÍA, PHD is chief of the Disparities Research Unit at Massachusetts General Hospital, and a professor in the Department of Psychiatry at Harvard Medical School. Alegría is currently the principal investigator of four research studies funded by the National Institutes of Health: The Impact of Medicaid Plans on Access to and Quality of Substance Use Disorder Treatment, Building Infrastructure for Community Capacity in Accelerating Integrated Care, Building Community Capacity for Disability Prevention for Minority Elders and Latino Youths in Coping with Discrimination: A Multi-Level Investigation in Micro- and Macro- Time.

MARY T. BASSETT, MD, MPH,was recently appointed as the Health Commissioner for the state of New York. Bassett has dedicated her career to advancing health equity. Dr. Bassett currently serves as the director of the François-Xavier Bagnoud (FXB) Center for Health and Human Rights at Harvard University and the FXB professor of the Practice of Health and Human Rights at the Harvard T.H. Chan School of Public Health. Prior to joining the FXB Center, she served as New York City's commissioner of health from 2014 to 2018.

RAYMOND BAXTER, PHD, is co-chair of the National Academies of Science, Engineering, and Medicine (NASEM) Roundtable on Population Health, serves on the CDC Foundation Board of Directors, is a trustee of the Blue Shield of CA Foundation, and serves as an advisor to the deans of the University of California Berkeley School of Public Health and the University of California San Francisco School of Nursing. He most recently served as president and CEO of Blue Shield of California Foundation, leading its mission to make California the healthiest state and end domestic violence by addressing the root causes of ill health and inequity. For 15 years, Baxter was Kaiser Permanente's senior vice president for community benefit, research, and health policy. Previously, he headed the San Francisco Department of Public Health, the New York City Health and Hospitals Corporation, and The Lewin Group.

JULIET K CHOI, JD, is chief executive officer of the Asian and Pacific Islander American Health Forum, a national health justice organization that influences policy, mobilizes communities, and strengthens programs and organizations to improve the health of Asian Americans, Native Hawaiians, and Pacific Islanders. She is an accomplished cross-sector leader and coalition builder who specializes in change management, system reform, and stakeholder relations, particularly in the areas of immigration, civil rights, healthcare, and disaster relief.

MICHAEL CRAWFORD, MBA, MHL, is the associate dean for strategy, outreach, and innovation at the Howard University College of Medicine and founding executive director of Howard University's 1867 Health Innovations Project. Prior to Howard University, Crawford served as the chief of staff at Unity Health Care, Inc., one of the largest health center networks in the United States. Prior to Unity, Crawford held domestic and international leadership positions at Johnson & Johnson, GlaxoSmithKline, and Gannett Company. Crawford brings expertise at the intersection of digital health equity, data, strategy, product development, policy, and operations. Crawford's work focuses on developing scalable digital health and data models to help enhance health access, outcomes, and affordability for medically underserved and vulnerable populations.

FERNANDO DE MAIO, PHD, is the director of research and data use for the Center for Health Equity at the American Medical Association and a professor of sociology at DePaul University. His research and teaching interests lie primarily within medical sociology and social epidemiology, with a focus on the concept of structural violence. His work has been guided by the notion of "radical statistics"—the idea that statistical analysis can be used to not just describe the world, but to change it. He is the author of *Global Health Inequities* (Palgrave Macmillan, 2014) and co-editor of *Community Health Equity: A Chicago Reade*r (University of Chicago Press, 2019) and *Unequal Cities: Structural Racism and the Death Gap in America's 30 Largest Cities* (Johns Hopkins University Press, 2021).

KAREN DESALVO MD, MPH, MSC, is the chief health officer at Google. DeSalvo served as acting assistant secretary for health at the U.S. Department of Health and Human Services in the Obama administration. Under her leadership, HHS set and met historic goals in payment reform, supported transformed models of care delivery, including in primary care, and changed the approach to information distribution in the health system. She also served as the National Coordinator for Health Information Technology, where she set national strategy and policy on health information technology and championed interoperability in health settings.

ABIGAIL ECHO-HAWK, MA (PAWNEE), is the executive vice president of the Seattle Indian Health Board and the director of the Urban Indian Health Institute, a tribal epidemiology center. She works to support the health and well-being of urban Indian communities and tribal nations across the United States. Echo-Hawk has been recognized as a national leader in decolonizing data for Indigenous people, by Indigenous people.

THOMAS LAVEIST, PHD, is dean of the School of Public Health and Tropical Medicine at Tulane University in New Orleans, LA. Before joining Tulane, LaVeist was chairman of the Department of Health Policy and Management at the George Washington University, Milken Institute School of Public Health, and spent 25 years on the faculty of the Johns Hopkins Bloomberg School of Public Health. LaVeist's research focuses on the development of policy and interventions to address race disparities in health-related outcomes.

ALEXIS C. MADRIGAL is a writer at *The Atlantic* and the co-founder of the COVID Tracking Project. He's been a visiting scholar at the University of California Berkeley's Information School as well as the Center for Science, Technology, Medicine, and Society.

JOHN LUMPKIN MD, MPH, is president of the Blue Cross and Blue Shield of North Carolina Foundation, since April 2019. He leads the organization in pursuit of its stated mission to improve the health and well-being of everyone in North Carolina by focusing on transforming the health care system (including oral health), expanding access to healthy food, supporting a healthy start in life for children, improving the physical conditions where people live, and strengthening the ability of communities to improve health.

AMY O'HARA PHD, MA, is a research professor in the Massive Data Institute and executive director of the Federal Statistical Research Data Center at Georgetown University's McCourt School for Public Policy. She also leads the Administrative Data Research Initiative, improving secure, responsible data access for research and evaluation, and is co-founder of the Civil Justice Data Commons. O'Hara addresses risks involved with data sharing by connecting practices across the social, health, computer, and data sciences. Her research focuses on population measurement, data quality, and record linkage. Prior to joining Georgetown, O'Hara was a senior executive at the U.S. Census Bureau, where she founded the administrative data curation and research unit.

JONATHAN PERLIN MD, PHD, is president, clinical operations and chief medical officer at HCA Healthcare, where he leads a team in using a learning health system model for improving care at the system's 185 hospitals and 2,200 sites of care. The effort achieved national recognition for preventing elective pre-term deliveries, reducing maternal mortality, increasing sepsis survival, and developing public-private-academic partnerships for improving infection prevention and treating COVID-19. Prior to HCA, Perlin was under secretary for health in the U.S. Department of Veterans Affairs. He is a MedPAC commissioner, a Congressional Budget Office health advisor, chairs the National Quality Forum, and is an elected member of the National Academy of Medicine. He has faculty appointments at Vanderbilt University and at Virginia Commonwealth University.

NINEZ PONCE MPP, PHD, is a professor in the University of California Los Angeles (UCLA) Fielding School of Public Health, director of the UCLA Center for Health Policy Research, and principal investigator for the California Health Interview Survey. Her research contributes to the elimination of racial/ethnic/social disparities in health. Ponce recently served on the Board of Scientific Counselors, National Center for Health Statistics. She has served on committees for the National Academy of Sciences and the National Quality Forum, where her expertise has focused on setting guidance for health systems in the measurement and use of social determinants of health as tools to monitor health equity. In 2019, Ponce and her team received the AcademyHealth Impact award for their contributions to population health measurement to inform public policies.

CHESLEY RICHARDS, MD, MPH, FACP, served at the Centers for Disease Control and Prevention (CDC) from 1998 to 2020 in several roles, including as deputy director for public health science and surveillance. In this position, he was responsible for strengthening CDC's science foundation by working across the Office of Science, the Office of Laboratory Science and Safety, the Center for Surveillance, Epidemiology, and Laboratory Services, and the National Center for Health Statistics. A primary focus of his role was to advance an agency-wide public health data strategy and serve as an advisor to the CDC director.

JAVIER ROBLES, JD, is a faculty member and professor of the Kinesiology and Health Department and is the director of the Center for Disability Sports, Health and Wellness at Rutgers University. He is the chair of the New Jersey Disabilities Covid-19 Action Committee and was appointed by Gov. Murphy to the Puerto Rico commission. Robles is a board member of the United Spinal National Board and the vice president of the Latino Action Network of New Jersey. He is past president of Thisabled, LLC, an organization that provides support to persons with disabilities through self-empowerment and perseverance. He is the founder of the Facebook group "People with Disabilities Helping Each Other Survive the Coronavirus." Robles has written for numerous publications including, Latinos NJ, ThisAbled Nation, and New Mobility. One of his poems was recently published in the book *Access Granted*.

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