

The Use of Race and Ethnicity in Biomedical Research

PUBLIC BRIEFING BOOK

January 31, 2024

VIRTUAL MEETING

Link for public session

Public Workshop, January 31 (9:00 AM – 4:30 PM ET)

Webcast Link: https://www.nationalacademies.org/event/41676_01-2024_the-use-of-race-and-ethnicity-in-biomedical-research-meeting-3

The Use of Race and Ethnicity in Biomedical Research

Meeting 3: January 31, 2024

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Agenda

Committee on the Use of Race and Ethnicity in Biomedical Research

Public Workshop

January 31, 2024

WORKSHOP OBJECTIVES

- Consider how race and ethnicity are used through the research process
- Learn about new research approaches and alternatives to using race and ethnicity categories
- Explore different research contexts in which race and ethnicity arise (e.g., in the clinic, development of clinical tools, industry)

WEDNESDAY, JANUARY 31, 2024

9:00 am – 4:30 pm ET

OPEN SESSION – PUBLIC WORKSHOP

Webcast: https://www.nationalacademies.org/event/41676_01-2024_the-use-of-race-and-ethnicity-in-biomedical-research-meeting-3

SESSION I: Human Physical Variation and Effects on Health Research

Session Objectives:

- Learn how human phenotypic variation in skin pigmentation, for example, can be characterized
- Discuss how variation in traits like skin color and hair contributes to downstream effects in biomedical research
- Consider new approaches to measure and account for phenotypic variation in research

9:00 – 9:05 AM ET

Welcome and Overview

M. Roy Wilson, *Committee Chair*
President Emeritus
Wayne State University

9:05 – 9:10 AM

Introduction to the Session

Neil Powe, *Session Moderator*
Constance B. Wofsy Distinguished Professor and Vice-Chair of Medicine
University of California San Francisco

9:10 – 9:55 AM

Speakers' Opening Remarks

Committee on the Use of Race and Ethnicity in Biomedical Research

Nina Jablonski

Atherton Professor, Evan Pugh University Professor Emerita of Anthropology
The Pennsylvania State University

Heather Norton

Associate Professor and Director of Graduate Studies
University of Cincinnati

Kimani Toussaint

Senior Associate Dean for Research and Strategic Initiatives
Thomas J. Watson Sr. Professor of Science
Brown University

9:55 – 10:20 AM

Panel Discussion

10:20 – 10:35 AM

BREAK

SESSION II: Alternatives to Using Race and Ethnicity Categories in Research

Session Objectives:

- Discuss alternatives to using race and ethnicity categories (e.g., OMB categories) in research
- Explore qualitative and quantitative methods for examining race and ethnicity in research
- Consider the advantages and disadvantages of collecting race and ethnicity data

10:35 – 10:40 AM

Introduction to the Session

Roland J. Thorpe, Jr., *Session Moderator*

Professor and Associate Vice Provost of Faculty Diversity
Johns Hopkins Bloomberg School of Public Health

10:40 – 11:25 AM

Speakers' Opening Remarks

Ellis Monk

Professor of Sociology
Harvard University

Paris "AJ" Adkins-Jackson

Assistant Professor of Epidemiology and Sociomedical Sciences
Columbia Mailman School of Public Health

Chandra L. Ford

Professor of Behavioral, Social and Health Education Sciences
Professor of African American Studies
Emory University

11:25 – 11:50 AM

Panel Discussion

11:50 AM – 12:30 PM

BREAK

SESSION III: Race and Ethnicity in Clinical Data Collection, Algorithms, and Tools

Session Objectives:

- Examine how race and ethnicity are currently used in clinical algorithms and decision-making tools and discuss the effects of this use
- Explore whether and how race and ethnicity could be used in the development of future clinical algorithms

12:30 – 12:35 PM

Introduction to the Session

Shyam Visweswaran, *Session Moderator*
Professor and Vice Chair of Clinical Informatics
University of Pittsburgh

12:35 – 1:20 PM

Speakers' Opening Remarks

Karen Wang
Assistant Professor of Internal Medicine and Health Informatics
Yale School of Medicine

Judy Wawira Gichoya
Associate Professor in the Department of Radiology and Imaging Sciences
Emory University School of Medicine

Marzyeh Ghassemi
Assistant Professor, Electrical Engineering and Computer Science and Institute for Medical Engineering & Science
Massachusetts Institute of Technology

1:20 – 1:45 PM

Panel Discussion

SESSION IV: Intersection of Race and Ethnicity in Biomedical Research and Clinical Applications

Session Objectives:

- Discuss how incorporating race and ethnicity (or not) in early-stage research influences applications in the clinic
- Explore best practices for collecting patient or research participant information for use in research

1:45 – 1:50 PM

Introduction to the Session

Carmen Guerra, *Session Moderator*
Ruth C. and Raymond G. Perelman Professor of Medicine
University of Pennsylvania

1:50 – 2:35 PM

Speakers' Opening Remarks

Valerie M. Harvey
Immediate Past President
Skin of Color Society

Ruth Carlos
Professor of Radiology and Assistant Chair for Clinical Research
University of Michigan

Elizabeth Selvin
Professor of Epidemiology
Johns Hopkins Bloomberg School of Public Health

2:35 – 3:00 PM **Panel Discussion**

3:00 – 3:10 PM **BREAK**

SESSION V: Industry Perspective on the Use of Race and Ethnicity in Research

Session Objectives:

- Discuss how regulatory considerations influence collection of race and ethnicity data.
- Explore incentives and disincentives for changing how race and ethnicity data are collected for industry research.

3:10 – 3:15 PM **Introduction to the Session**
Husseini Manji, *Session Moderator*
Co-Chair, UK Govt Mental Health Mission
Professor, Oxford University

3:15 – 4:00 PM **Speakers' Opening Remarks**

Vaibhav Narayan
Chief Industry Officer of UK Mental Health Mission
University of Oxford

Anne Lawrence
Head of US Clinical Operations
GSK

Pierre Theodore
Executive Director of Health Equity
Genentech

4:00 – 4:25 PM **Panel Discussion**

4:25 – 4:30 PM **Concluding Remarks**

4:30 PM **Adjourn**

Study Information

Committee on the Use of Race and Ethnicity in Biomedical Research

Study Sponsors: Doris Duke Foundation, Burroughs Wellcome Fund

Project Background

The Doris Duke Charitable Foundation has asked the National Academies of Sciences, Engineering, and Medicine to generate a report that guides the scientific community on the use of race and ethnicity in biomedical research, including identifying current research practices that are not grounded in rigorous scientific method and may ultimately exacerbate inequities in healthcare delivery and patient outcomes.

Statement of Task

An ad hoc committee of the National Academies of Sciences, Engineering, and Medicine will assess the current use of the social constructs of race and ethnicity in biomedical research and provide recommendations to guide the scientific community in the future use of race and ethnicity in biomedical research.

More specifically, the committee will:

- Document and evaluate how racialized group and ethnic categories are currently being used in biomedical research (e.g., as a descriptor, to stratify data, to apply race norming, to infer differences between groups due to environmental and social impacts), including describing consequences and contributions to health inequities in current clinical practices;
- Identify the circumstances in which it is appropriate to use the social constructs of race and ethnicity in biomedical research, for example in studying the health effects of racism, and the circumstances in which race and ethnicity should not be used to inform inferences;
- Review existing guidance for researchers on the use of race as a variable in biomedical research.

Based on its review of the literature and other expert input, the committee will develop a report with its findings, conclusions, and recommendations for entities such as researchers, funders, publishers, scientific and medical societies, health systems, and industry regarding:

- The use of race and ethnicity in biomedical research, including identifying current practices that should be continued, stopped, or modified;
- Policy changes to reform the use of race and ethnicity in biomedical research, with specific attention to the practice of race norming or race correction;
- Implementation strategies to help enhance the adoption of best practices across the biomedical research community.

The committee's work will focus on the use of racialized group and ethnic categories across the spectrum of biomedical research, including the development of clinical prediction models and other clinical decision tools. Related topics in the provision of clinical care, such as inequitable access to health care and racism in care delivery, are beyond the scope of this study.

Timeline

The committee will meet at least 5 times between October 2023 and July 2024, with the report being set to release in October 2024.

Project Website: <https://www.nationalacademies.org/our-work/the-use-of-race-and-ethnicity-in-biomedical-research>

Provisional Committee Membership

M. Roy Wilson, M.D., M.S. (Chair)
Wayne State University

Elizabeth O. Ofili, M.D., M.P.H.
Morehouse School of Medicine

Allison Aiello, Ph.D.
Columbia University

Neil R. Powe, M.D., M.P.H., M.B.A.
University of California, San Francisco

Efrén J. Flores, M.D.
Massachusetts General Hospital

Aliya Saperstein, Ph.D.
Stanford University

Carmen Guerra, M.D., M.S.C.E.
University of Pennsylvania

Roland Thorpe, Jr., Ph.D.
Johns Hopkins Bloomberg School of Public Health

Elizabeth Heitman, Ph.D.
University of Texas Southwestern Medical Center

Shyam Visweswaran, M.D., Ph.D.
University of Pittsburgh

Matthew F. Hudson, Ph.D., M.P.H.
Prisma Health

Genevieve L. Wojcik, Ph.D.
Johns Hopkins Bloomberg School of Public Health

Husseini K. Manji, M.D.
Oxford University

Ruqaiijah Yearby, J.D., M.P.H.
The Ohio State University

Amy Moran-Thomas, Ph.D.
Massachusetts Institute of Technology

Margaret Moss, Ph.D., J.D., RN
University of Minnesota School of Nursing

Study Staff

Sarah Beachy, Study Co-Director, RaceInBiomedResearch@nas.edu

Samantha Schumm, Study Co-Director

Joseph Tumfour, Associate Program Officer

Lydia Teferra, Research Associate

Ashley Pitt, Senior Program Assistant

Clare Stroud, Senior Board Director, Board on Health Sciences Policy

Francis Amankwah, Senior Program Officer, Board on Health Care Services

Ronique Taffe, Program Officer, Board on Population Health and Public Health Practice

Ben Weston, NAM Fellow

HEALTH AND MEDICINE DIVISION
BOARD ON HEALTH SCIENCES POLICY
BOARD ON POPULATION HEALTH AND PUBLIC HEALTH PRACTICE
BOARD ON HEALTH CARE SERVICES

Committee on the Use of Race and Ethnicity in Biomedical Research

Committee Member Biographies

M. Roy Wilson, M.D., M.S. (chair), is a physician, researcher, healthcare leader, and author. His 20-year history as leader of universities with budgets of \$550 million to \$1.8 billion is hallmarked by his successful efforts to expand access for underrepresented minorities, improve graduation rates, increase extramural funding, and execute ambitious fundraising campaigns. Dr. Wilson is chancellor emeritus of the University of Colorado Denver and Health Sciences Center and president emeritus of Wayne State University; he also served as deputy director of strategic scientific planning and program coordination at the National Institute on Minority Health and Health Disparities at the NIH. Previously, he was dean of the School of Medicine and Vice President for Health Sciences at Creighton University; president of the four-campus Texas Tech University Health Sciences Center; and dean of the medical school, president, and chair of the board of directors of Charles Drew University of Medicine and Science. He completed medical school and an ophthalmology residency at Harvard Medical School.

Allison Aiello, Ph.D., is the James S. Jackson Healthy Longevity Professor of Epidemiology at the Mailman School of Public Health and the Robert N. Butler Columbia Aging Center, where she leads a new program in Biosocial Science of Aging and Health Equity. Previously, Dr. Aiello led the Social Epidemiology Program as Professor of Epidemiology at the Gillings School of Global Public Health and became the Deputy Director of the National Longitudinal Study of Adolescent to Adult Health (Add Health) in 2021. She was awarded the 2019 Carol Rowland Hogue Award for Outstanding Mid-Career Achievement in Epidemiology from the Society for Epidemiological Research for her achievements. Dr. Aiello's research focuses on identifying the processes by which health inequities in aging emerge across the life course, with the goal of uncovering points of intervention. Her research program has focused on some of today's most pressing and complex health exposures and conditions, including socioeconomic inequalities, biological aging, Alzheimer's disease, immunity, and susceptibility to infectious diseases. She received her Ph.D. in epidemiology from Columbia University with distinction and was awarded the Anna C. Gelman Award for outstanding achievement and promise in epidemiology.

Efrén J. Flores, M.D., is an Associate Professor at Harvard Medical School and serves as faculty in Thoracic Imaging at Massachusetts General Hospital (MGH), where completed his Diagnostic Radiology residency and fellowship. Dr. Flores is a nationally recognized health services researcher focused on understanding health disparities and advancing health equity among historically underserved racial and ethnic minority communities. He has served in several leadership roles at MGH, including his current role as Vice-Chair for Radiology Diversity Equity, and Inclusion (DEI), and as the founding Director of the Radiology Inclusion and Systemic Equity (RISE) Center. Dr. Flores is recognized as a national thought leader in health disparities research as evidenced by numerous awarded grants, invited presentations

nationally, and peer-reviewed publications. His health equity work is guided by the overarching goal of fostering trust and a sense of belonging. In recognition for his work, Dr. Flores was selected as one of the inaugural NAM Scholars in Diagnostic Excellence in 2021, and he currently serves on several institutional and national committees, including as Co-Chair of the Health Equity Committee for the Radiological Society of North America and as Associate Editor of Health Equity for the Journal of the American College of Radiology.

Carmen Guerra, M.D., M.S.C.E., is the Ruth C. and Raymond G. Perelman Professor of Medicine at the Perelman School of Medicine at the University of Pennsylvania. She is also the Vice Chair of Diversity and Inclusion for the Department of Medicine, and the Associate Director of Diversity and Outreach for the Abramson Cancer Center (ACC) where she leads Community Outreach and Engagement, including a Genentech-funded Cancer Clinical Trials Ambassador Program that promotes clinical trial awareness through peer-to-peer education. A general internist trained in epidemiology and a health equity researcher, Dr. Guerra has designed and evaluated interventions to increase access to cancer screening and cancer clinical trials for underserved populations. Dr. Guerra serves on the American Cancer Society's Guideline Development Group and is an author of the American Cancer Society's current colorectal, cervical, and lung cancer screening guidelines as well as the current HPV vaccination guidelines. In recognition of her contributions, Dr. Guerra received the American Cancer Society's St. George Medal in 2017, the Association of Community Cancer Centers Research Award in 2022, and the American Society of Clinical Oncology Excellence in Health Equity Award in 2023. She is also a member of the advisory board of Guardant Health, a company developing blood tests for colorectal cancer, and is the US Deputy Chair of the Health Equity Workgroup of the Multicancer Early Detection Consortium.

Elizabeth Heitman, Ph.D., is Professor in the Program in Ethics in Science and Medicine and Department of Psychiatry at the University of Texas Southwestern Medical Center in Dallas, Texas. Her work focuses on cultural aspects of ethics in clinical medicine, biomedical science, and public health, particularly international standards of research ethics and education in the responsible conduct of research (RCR). Dr. Heitman teaches research ethics and RCR across UT Southwestern through the Center for Translational Medicine and Graduate School of Biomedical Sciences, and she leads ethics education for two NIH training grants on cardiovascular health disparities, Obesity Health Disparities PRIDE and the Jackson Heart Study Graduate Training and Education Center at the University of Mississippi Medical Center. Dr. Heitman co-directs a Fogarty International Center-sponsored research ethics education program with Eduardo Mondlane University in Mozambique and is an advisory committee member for similar programs in Colombia and the Caribbean. She is a National Associate of the US National Research Council and has been chair or member of eight US National Academy of Sciences programs in research integrity education in the Middle East, North Africa, Indonesia, and Malaysia. In 2015-16 she co-chaired the NASEM Committee on Gene Drive Research with Non-Human Organisms.

Matthew F. Hudson, Ph.D., M.P.H., is the Director of Cancer Care Delivery Research (CCDR) at Prisma Health (Greenville, South Carolina), and Professor of Medicine at the University of South Carolina School of Medicine Greenville. Dr. Hudson conducts and oversees research on patient, provider, and organization-based interventions improving cancer care outcomes and patient well-being. Dr. Hudson served on multiple National Institute of Minority Health and Health Disparities study sections designed to augment workforce diversity. Dr. Hudson's own research examines racial differences in pain reports and management experiences among patients with cancer. Dr. Hudson served the Patient Centered Outcomes Research Institute (PCORI) as a member of their Patient Engagement Advisory Panel; he also

co-authored the PCORI report, Equity and Inclusion Guiding Engagement Principles. Dr. Hudson received his Ph.D. from Dartmouth College, M.P.H. from the University of California at Berkeley, and B.A. from the University of San Francisco. Dr. Hudson also received a certificate from the National Cancer Institute's Multilevel Intervention Training Institute (MLTI), and subsequently served MLTI as a small group junior faculty member.

Husseini K. Manji, M.D., is Co-chair of the UK Mental Health Mission and a visiting professor at Oxford University. Previously, Dr. Manji was Global Head of Science for Minds at Johnson & Johnson (J&J), where he led a global team to discover and develop new therapeutics for major neurologic, psychiatric, and pain-related diseases with a high unmet need for effective treatments. Dr. Manji's research has helped to conceptualize severe neuropsychiatric disorders as genetically influenced disorders of synaptic and neural plasticity and led to the investigation of key novel therapeutics. The major focus of his research has been the investigation of disease- and treatment-induced changes in gene and protein networks that regulate synaptic and neural plasticity in brain and behavior disorders. Before joining J&J, Dr. Manji was Director of the Mood and Anxiety Disorders Program, the largest research program of its kind in the world, at the National Institute of Mental Health. His work led to approval of the first novel antidepressant mechanism in decades, SPRAVATO (esketamine) nasal spray for adults with treatment-resistant major depressive disorder, by the U.S. Food and Drug Administration, Canada, and the European Commission. Dr. Manji is a member of the National Academy of Medicine. He also serves on the scientific advisory boards of the Dana Foundation and of Vanna Health.

Amy Moran-Thomas, Ph.D., is Associate Professor of Anthropology at the Massachusetts Institute of Technology and a faculty member in the program in History, Anthropology, and STS (Science, Technology, and Society). She is interested in how social perspectives on design can contribute to producing more equitable technologies. Her work combines insights from ethnographies of science and medicine; material histories of design; and STS perspectives on health and environment. Her essays helped draw attention to longstanding racial biases encoded in color-sensing medical devices and catalyzed clinical reexaminations of the pulse oximeter, including recent FDA hearings that led to new safety advisories. Prof. Moran-Thomas' writings have appeared in publications such as *New England Journal of Medicine* and *Wired*. Her first book, *Traveling with Sugar: Chronicles of a Global Epidemic* (2019), offers an anthropological account of diabetes technologies in use and the lives they shape in global perspective. Research and writing were supported by the Mellon-American Council of Learned Societies (ACLS), the Wenner-Gren Foundation, and the Rachel Carson Center for Environment and Society and received five book awards, including the Wellcome Foundation's Medal for Anthropology as Applied to Medical Problems. Professor Moran-Thomas received her Ph.D. in Anthropology from Princeton University in 2012.

Margaret Moss, Ph.D., J.D., RN, is an enrolled member of the Mandan, Hidatsa, and Arikara Nation in North Dakota. She is currently Professor and Associate Dean for Nursing and Health Policy at the University of Minnesota, School of Nursing. She holds both Nursing and Juris Doctorates. She has been a nurse for 34 years and an academic for 23 years across four universities. Previously at the University of British Columbia (UBC), she was a Professor in the Faculty of Applied Science, School of Nursing (20%) and Director of the UBC First Nations House of Learning (80%). During this time, she served as Interim Associate Vice President Equity & Inclusion at UBC (2022). Dr. Moss sat on the American Academy of Nursing Board of Directors in 2021-2023, is a new member of the National Academy of Medicine (2022), and is a member of the National Academies Board on Population and Public Health. Dr. Moss was a

committee member on the recent consensus report (2023) *Federal Policy to Advance Racial, Ethnic and Tribal Health Equity*. She wrote an award-winning text, *American Indian Health and Nursing* (2015) followed by *Health Equity and Nursing* (2020). She co-led the development and launch of the *UBC Indigenous Strategic Plan* (2020) and was a consultant on the *In Plain Sight Report: Addressing Anti-Indigenous Racism in Healthcare in BC* for the Minister of Health (2020). Dr. Moss was named an Inaugural member of the *Forbes 50 over 50 Impact list 2021*. She was a RWJF Health Policy Fellow, staffing the US Senate Special Committee on Aging, and was a Fulbright Chair at McGill University-Montreal, QC, Canada.

Elizabeth O. Ofili, M.D., M.P.H., is a Professor of Medicine at Morehouse School of Medicine and a practicing cardiologist with Morehouse Healthcare in Atlanta, Georgia. She serves as Chief Medical Officer for Morehouse Choice Accountable Care Organization, a Center for Medicare and Medicaid Services Shared Savings Program, which includes Federally Qualified Health Centers across the state of Georgia. Dr. Ofili is a nationally and internationally recognized clinician scientist with particular focus on cardiovascular disparities and women's health. In 2002, as president of the Association of Black Cardiologists (ABC), she led the initiative to implement the landmark African American Heart Failure Trial (AHEFT), whose findings changed practice guidelines for the treatment of heart failure in African Americans. Dr. Ofili is the Founder and Chief Executive Officer of AccuHealth Technologies Inc./Health 360x™ a patient-centered platform for population health management and clinical trial diversity. Dr. Ofili is the immediate past Chair of the Board of the Association of Black Cardiologists. She serves as Chair of the Board of Directors of Alliant Health Group, a nonprofit Quality Improvement Organization. Dr. Ofili is a principal investigator (PI) in the National Research Mentoring Network and contact PI of the Coordination and Evaluation Center for the NIH Faculty Institutional Recruitment for Sustainable Transformation (FIRST) Program for Inclusive Excellence. She serves as PI of the Amgen-sponsored African American Heart Study, multi-PI of the Georgia Clinical and Translational Science Alliance, and contact PI of the Research Centers in Minority Institutions Coordinating Center. She serves in advisory roles for Amgen's Rise program and the Bristol-Meyers-Squib-Pfizer alliance initiative. Dr. Ofili has received many awards for her contributions and is an elected member of the National Academy of Medicine. Dr. Ofili graduated with distinction from Ahmadu Bello University School of Medicine in Nigeria and received an M.P.H from Johns Hopkins University.

Neil R. Powe, M.D., M.P.H., M.B.A., is Chief of Medicine at the Priscilla Chan and Mark Zuckerberg San Francisco General Hospital and the Constance B. Wofsy Distinguished Professor at the University of California, San Francisco. He also serves as the Chief Science Officer for the Commonwealth Fund. Dr. Powe led the National Kidney Foundation-American Society of Nephrology Task Force on Reassessing the Inclusion of Race in Diagnosing Kidney Diseases that led to elimination of race from estimation of kidney function. As member and now chair of the Journal of the American Medical Association Oversight Committee, he provided important decision making regarding a podcast on structural racism. Dr. Powe is a member of the National Academy of Medicine and has served on previous National Academies consensus study committees. Among his honors are the Diversity Award from the Association of Professors of Medicine, the John M. Eisenberg Award for Career Achievement in Research and the Robert J. Glaser Award from the Society of General Internal Medicine, the David Hume Memorial Award from the National Kidney Foundation, the 2021 John Phillips Memorial Award for Distinguished Contributions in Clinical Medicine from the American College of Physicians, and the Cato Laurencin Lifetime Research Award from the National Medical Association. Dr. Powe holds an M.D. and M.P.H

from Harvard, and at the University of Pennsylvania, he completed residency, was a Robert Wood Johnson Clinical Scholar, and earned an M.B.A.

Aliya Saperstein, Ph.D., is the Benjamin Scott Crocker Professor in human biology and a professor of sociology at Stanford University. Her research focuses on the conceptualization and measurement of race/ethnicity and the consequences of these methodological decisions for studies of stratification and health disparities, including in the field of precision medicine research. Her work has been published in *Science*, the *Proceedings of the National Academy of Sciences*, *American Journal of Sociology*, and the *Annual Review of Sociology*, among others. Dr. Saperstein has been a Visiting Scholar at Sciences Po and the Russell Sage Foundation. Her scholarship has been honored with multiple article awards as well as the Early Achievement Award from the Population Association of America. Saperstein has a Ph.D. in sociology and demography from the University of California-Berkeley.

Roland J. Thorpe, Jr., Ph.D., is a Professor in the Department of Health, Behavior, and Society, Founding Director of the Program of Men's Health Research in the Hopkins Center for Health Disparities Solutions, and Director of the Johns Hopkins Alzheimer's Disease Resource Center for Minority Aging Research at the Johns Hopkins Bloomberg School of Public Health. Dr. Thorpe is a social epidemiologist and gerontologist whose research focuses on how social determinants of health impact health and functional outcomes among men across the life course. Dr. Thorpe serves as principal investigator (PI) on several NIH-funded grants and is a multiple PI of the Artificial Intelligence/Machine Learning consortium to Advance Health Equity and Researcher Diversity (AIM-AHEAD). Dr. Thorpe is the inaugural Associate Vice Provost for Faculty Diversity at Johns Hopkins University. He is a Fellow of the Gerontological Society of America and the Academy of Behavioral Medicine Research. Dr. Thorpe earned a bachelor's in theoretical mathematics from Florida A&M University, a master's in statistics, and a Ph.D. in clinical epidemiology with a graduate minor in gerontology from Purdue University. He received postdoctoral training in health disparities and gerontology from the Division of Geriatric Medicine and Gerontology at the Johns Hopkins School of Medicine. Dr. Thorpe is a member of scientific advisory boards, including the National Center for Health Statistics Board of Scientific Counselors, and is the editor-in-chief of *Ethnicity & Disease*.

Shyam Visweswaran, M.D., Ph.D., is a professor and Vice Chair of Clinical Informatics in the Department of Biomedical Informatics at the University of Pittsburgh. His research broadly focuses on computerized clinical decision support driven by machine learning; patient-specific modeling, in which statistical models are tailored to the characteristics of the patient at hand and optimized to perform well for that patient; and the development of statistical machine learning methods for causal discovery using electronic health record data, molecular data, or both. His current research focuses on cataloging clinical algorithms that incorporate a person's race and ethnicity and developing computational methods for understanding the effect of race and ethnicity on model bias. He holds an M.B., B.S. degree (M.D. equivalent) from the Jawaharlal Institute of Post-Graduate Medical Education and Research in Pondicherry, India, an M.S. degree in Physiology and Biophysics from the University of Illinois at Urbana-Champaign, and a Ph.D. in Intelligent Systems (artificial intelligence) from the University of Pittsburgh. He completed his neurology residency at Boston University.

Genevieve L. Wojcik, Ph.D., is an Assistant Professor of Epidemiology at the Johns Hopkins Bloomberg School of Public Health. As a statistical geneticist and genetic epidemiologist, her research focuses on method development for diverse populations, specifically understanding the role of genetic ancestry

and environment in genetic risk in admixed populations. Dr. Wojcik integrates epidemiology with statistical and population genetics to better understand existing health disparities in minority populations, as well as underserved populations globally. In 2021, she was the recipient of one of NHGRI's Genomic Innovator Awards (R35). She is a long-standing member of multiple NHGRI consortia focused on diverse populations, such as the Population Architecture using Genomics and Epidemiology (PAGE) Study and the PRIMED consortium. Prior to her faculty appointment, Dr. Wojcik was a postdoctoral research scholar at Stanford University in the Departments of Genetics and Biomedical Data Science. She received her Ph.D. in Epidemiology and M.H.S. in Human Genetics/Genetic Epidemiology from the Johns Hopkins Bloomberg School of Public Health and her B.A. in Biology from Cornell University. She was recently a member of the National Academies Committee on the Use of Race, Ethnicity, and Ancestry as Population Descriptors in Genomics Research, which published its report in 2023.

Ruqaiijah Yearby, J.D., M.P.H., is the inaugural Kara J. Trott Professor in Health Law at the Moritz College of Law, Professor in the Department of Health Services Management and Policy at the College of Public Health, and a faculty affiliate of the Kirwan Institute for the Study of Race and Ethnicity at The Ohio State University. An expert in health policy and civil rights, Professor Yearby has received over \$5 million from the National Institutes of Health (NIH) to study structural racism and discrimination in vaccine allocation and from the Robert Wood Johnson Foundation to study the equitable enforcement of housing laws and structural racism in health care. She was a keynote speaker for the 5th Annual Conference of the ELSI Congress and has served as a reviewer for NIH, the Swiss National Science Foundation, and the Wellcome Trust. Yearby is on the editorial board of the American Journal of Bioethics and is a Committee Member for the U.S. Department of Health and Human Services, Secretary's Advisory Committee on Human Research Protections. Her work has been published in the American Journal of Bioethics, American Journal of Public Health, Health Affairs, and the Oxford Journal of Law and the Biosciences.

Workshop Information

Committee on the Use of Race and Ethnicity in Biomedical Research

January 31st, 2024

Speaker Biographies

Paris "AJ" Adkins-Jackson, Ph.D., M.P.H., is a multidisciplinary community-partnered health equity researcher and Assistant Professor in the Departments of Epidemiology and Sociomedical Sciences in the Mailman School of Public Health at Columbia University. Dr. AJ's research investigates the role of structural racism on healthy aging for historically marginalized populations like Black and Pacific Islander communities. Her primary project examines the role of life course adverse community-level policing exposure on psychological well-being, cognitive function, and biological aging for Black and Latinx/a/o older adults. Her secondary project tests the effectiveness of an anti-racist multilevel pre-intervention restorative program to increase community health and institutional trustworthiness through multisector community-engaged partnerships. Dr. AJ is an HBCU alumna of the psychometrics doctoral program at Morgan State University and a board member of the Society for the Analysis of African American Public Health Issues.

Ruth Carlos, M.D., M.S., FACR, is a Professor of Radiology, and serves as the Assistant Chair for Clinical Research at the University of Michigan. She received her medical degree from and completed her diagnostic radiology residency at the University of Chicago, and fellowship at the University of Michigan in Ann Arbor, joining the faculty at the University of Michigan in 1998. She has received a Master's Degree in the School of Public Health at the University of Michigan. Dr. Carlos has received numerous awards and honors. She is an elected fellow of the American College of Radiology (ACR), and the Society of Computed Tomography and Magnetic Resonance (SCBT-MR). She has received the Gold Medal from the Association of University Radiologists (AUR), Distinguished Educator Award from the Radiological Society of North America (RSNA), the Stanford Medicine X Research Challenge Grand Prize. A funded investigator of the National Institutes of Health (NIH), she has been recognized for her research by induction into the Academy of Radiology Research Council of Distinguished Investigators reflecting top ten percent of all academic radiology faculty and awarding of the Paul C. Hodges Excellence Award. Dr. Carlos currently chairs the GE AUR Research Radiology Academic Fellowship (GERRAF), a national program supporting early-stage investigators in health services research and care delivery. As an alumnus of this program founded in 1992, she has mentored more than 10 current and past award recipients. Her mentorship has been recognized by the Michigan Institute for Clinical and Health Research Distinguished Clinical and Translational Research Mentor Award. She is a frequently invited guest speaker at academic institutions and national/international meetings.

Chandra L. Ford, Ph.D., M.L.I.S., M.P.H., is Professor of Behavioral, Social and Health Education Sciences in the Rollins School of Public Health and of African American Studies at

Emory University. Prior to joining Emory she founded the Center for the Study of Racism, Social Justice and Health, which moved with her to Atlanta, GA in 2023. Dr. Ford is lead editor (with Derek Griffith, Marino Bruce and Keon Gilbert) of *Racism: Science & Tools for the Public Health Professional* (APHA Press, 2019), which the American Library Association named an Outstanding Academic Title for 2020. She earned her doctorate in Health Behavior from the UNC Gillings School of Global Public Health and completed postdoctoral fellowships in Social Medicine (at UNC School of Medicine) and Epidemiology (at Columbia University's Mailman School of Public Health), the latter as a W. K. Kellogg Foundation Kellogg Health Scholar. Her areas of expertise include the conceptualization and measurement of race, ethnicity and racism constructs, health equity applications of Critical Race Theory; and the health and healthcare implications of racism. Her work is anchored in Public Health Critical Race Praxis (PHCRP), a 4-stage adaptation of CRT that she co-originated with Collins Airhihenbuwa to guide antiracism approaches to health equity research. Dr. Ford serves the profession widely. She is a longstanding member of the American College of Epidemiology's Minority Affairs Committee and a former president of the Society for the Analysis of African American Public Health Issues. She has received many teaching awards and several notable honors, including the 2020 Wade Hampton Frost Award from the Epidemiology Section of the American Public Health Association and a Lifetime Achievement Award from the Association of Black Women Physicians.

Marzyeh Ghassemi, Ph.D., is an Assistant Professor at MIT in Electrical Engineering and Computer Science (EECS) and Institute for Medical Engineering & Science (IMES), and a Vector Institute faculty member holding a Canadian CIFAR AI Chair and Canada Research Chair. She holds a Herman L. F. von Helmholtz Career Development Professorship and was also named one of MIT Tech Review's 35 Innovators Under 35. Previously, she was a Visiting Researcher with Alphabet's Verily and an Assistant Professor at University of Toronto. Prior to her PhD in Computer Science at MIT, she received an MSc. degree in biomedical engineering from Oxford University as a Marshall Scholar, and B.S. degrees in computer science and electrical engineering as a Goldwater Scholar at New Mexico State University. Professor Ghassemi is on the Senior Advisory Council of Women in Machine Learning (WiML) and organized its flagship workshop at NIPS during December 2014. She has also organized and MIT's first Hacking Discrimination event and was awarded MIT's 2018 Seth J. Teller Award for Excellence, Inclusion and Diversity. She also served on MIT's Presidential Committee on Foreign Scholarships from 2015-2018, working with MIT students to create competitive applications for distinguished international scholarships. In 2015, she also worked as a graduate student member of MIT's CJAC (Corporation Joint Advisory Committee on Institute-wide Affairs), a committee to which the Corporation can turn for consideration and advice on special Institute-wide issues.

Judy Wawira Gichoya, M.D., M.S., is Associate Professor in the Department of Radiology and Imaging Sciences at Emory University School of Medicine. Dr. Gichoya is a multidisciplinary researcher, trained as both an informatician and an Interventional radiologist. Dr. Gichoya is a member of the Cancer Prevention and Control Research Program at Winship Cancer Institute.

She holds professional memberships with Radiological Society of North America, American College of Radiology, Society of Interventional Radiology, Society of Imaging Informatics in Medicine, and American Medical Informatics Association. Dr. Gichoya earned her Medical Degree from Moi University in Kenya. She completed her medical internship at Kiambu District Hospital. She earned a Master of Science in Health Informatics from Indiana University Purdue University in Indianapolis, Indiana. In addition, she completed post-doctoral training in informatics at Regenstrief Institute in Indianapolis, Indiana, and a residency in diagnostic radiology at Indiana University. Prior to arriving at Emory, she completed a fellowship in interventional radiology at Oregon Health Sciences University in Portland, Oregon. Dr. Gichoya's research interests include studying clinical disparities for minimally invasive procedures, validating machine learning models for health in real clinical settings, exploring explainability, fairness, and a specific focus on how algorithms fail. She has worked on the curation of datasets for the SIIM (Society for Imaging Informatics in Medicine) hackathon and ML committee. She volunteers on the ACR and RSNA machine learning committees to support the AI ecosystem to advance development and use of AI in medicine.

Valerie M. Harvey, M.D., M.P.H., FAAD, earned her undergraduate and medical degrees from the University of Virginia. She completed her residency and Chief Residency at the University of Maryland Medical Center. She later received a Master of Public Health from the Johns Hopkins Bloomberg School of Public Health. Dr. Harvey is a Fellow of the American Academy of Dermatology. As a highly skilled, board-certified dermatologist with over a decade of clinical experience, Dr. Harvey provides advanced patient-centered care for diseases of the skin, hair, and nails. Dr. Harvey is an expert in treating both common and uncommon skin conditions including acne, eczema, psoriasis, various forms of hair loss, including alopecia areata, and skin cancer. Dr. Harvey also specializes in the diagnosis and treatment of pigmentary disorders such as hyperpigmentation and melasma, as well as other skin conditions which disproportionately impact minority patients. Her past research efforts have focused on studying gaps in melanoma outcomes and the use of dermatology services among the underserved. Dr. Harvey has authored many scientific articles and book chapters and has lectured at national medical meetings on these topics. Outside of her clinical practice, Dr. Harvey is an active leader in the dermatologic community. She serves on numerous boards and committees for the American Academy of Dermatology and the Skin of Color Society. She is the Immediate Past President of the Skin of Color Society and is also the Past President of the Virginia Dermatology Society.

Nina G. Jablonski, D.Phil., Ph.D., is an Atherton Professor and Evan Pugh University Professor Emerita of Anthropology at The Pennsylvania State University. A biological anthropologist and paleobiologist, she studies primate and human evolution, especially adaptations to the environment. Her research program is focused in four major areas. Her paleoanthropological research focuses primarily on the evolution of Old-World monkeys and draws upon field- and museum-based research undertaken in Africa and Asia. Her research on human adaptations to the environment centers on the evolution of human skin and skin pigmentation, including the health consequences of humanity's mostly naked and colorful skin.

The third area of research is related to the second and is concerned with understanding the history and social consequences of skin-color-based race concepts. The fourth area of concentration is science education for youth, especially education about human evolution and human physical diversity. Jablonski has directed and continues to lead major, externally funded research projects in all of these areas. She is a member of the National Academy of Sciences and the American Academy of Arts & Sciences and is one of the Vice-Presidents of The American Philosophical Society.

Anne Lawrence, ASQ CMQ/OE, is the Head of US Clinical Operations at GSK. With over 28 years' experience in global clinical trials, she is an expert in design and implementation of Risk Based Monitoring (RBM)/Risk Based Quality Management (RBQM), development of critical quality metrics, risk assessment, and key risk indicators. Prior to joining GSK, Lawrence was Executive Director of Central Monitoring and Risk Management at AbbVie.

Ellis Monk, Ph.D., is a Professor of Sociology at Harvard University. He earned his Ph.D. in Sociology from the University of California, Berkeley and a B.A. in Sociology from the University of Michigan, Ann Arbor. He previously taught at the University of Chicago and Princeton University. His research focuses on the comparative examination of social inequality, especially with respect to race and ethnicity, in global perspective. This research uses both quantitative and qualitative methods, while drawing heavily upon contemporary theories of social cognition and categories. By deeply engaging with issues of measurement and methodology, it examines the complex relationships between social categories and social inequality; and extends into topics such as social demography, health, aging, social psychology, sociology of the body, political sociology, and comparative/historical sociology.

Vaibhav A. Narayan Ph.D., M.B.A., is currently the Chief Industry Officer, UK Mental Health Mission at the University of Oxford, where he is responsible for bringing industry research and clinical trials into UK's mental health clinical research and delivery ecosystem. Vaibhav also holds a leadership advisory position at the Davos Alzheimer's Collaborative, a multi-stakeholder partnership committed to bringing data and insights from diverse cohorts around the world into Alzheimer's Disease research. Prior to joining UK Mental Health Mission, Vaibhav spent 13.5 years at Johnson & Johnson (J&J) where he was Vice President of Data Sciences and Digital Health and a senior leader in the Neuroscience Therapeutic Area. Prior to J&J, Vaibhav held various leadership roles in Informatics and Data Sciences at Eli Lilly & Co. and multiple biotech companies including Celera Genomics where he participated in the Human Genome Project. During his career, in addition to running large internal programs within organizations, Vaibhav has helped form and lead multiple multi-stakeholder innovation ecosystems and large scale public-private consortia (e.g. www.radar-cns.org, www.radar-ad.org) at the intersection of data science, digital health, and neuroscience. Vaibhav holds multiple patents and has co-authored > 80 scientific publications. Vaibhav obtained a PhD from Yale University in computational biology and an Executive MBA from Kellogg School of Management, Northwestern University.

Heather Norton, Ph.D., is a Molecular Anthropologist whose research focuses on understanding the evolution of complex traits in humans. She approaches this work using phenotypic, genetic, and evolutionary perspectives, with an emphasis on the human pigmentation phenotype. She received her Ph.D. in Anthropology from The Pennsylvania State University and joined the Anthropology Department at the University of Cincinnati in 2010. In her research Dr. Norton uses quantitative methods to characterize phenotypic variation in skin, hair, and iris pigmentation in diverse populations. She has worked to characterize genetic variants associated with this phenotypic variation and to place their frequency and distribution in the context of relevant population history. Dr. Norton is also interested in understanding the evolution of human skin pigmentation variation—specifically how the pigmentary phenotype has changed as humans expanded throughout Africa and into a diverse range of environments. Her work has contributed to a body of literature demonstrating that light skin color in humans has evolved through independent genetic mechanisms in different populations that have been targeted by strong natural selection. More recently Dr. Norton has begun to explore other aspects of human skin variation, particularly those related to skin aging. Her research has been funded by the National Institute of Health, National Institute of Justice, and Procter & Gamble.

Elizabeth Selvin, Ph.D., is a Professor of Epidemiology at the Johns Hopkins Bloomberg School of Public Health and holds a joint appointment in the School of Medicine, Division of General Internal Medicine. Dr. Selvin has devoted her career to leading translational research projects designed to evaluate and improve screening, diagnosis, and patient care for persons with diabetes. Her work has directly influenced clinical practice guidelines for diagnosis and management of diabetes. In 2013, she was awarded the Harry Keen Memorial Award by the International Diabetes Epidemiology Group of the International Diabetes Federation for her contributions to the field. She was the 2020 winner of the Kelly M. West Award for Outstanding Achievement in Epidemiology from the American Diabetes Association. Since the start of her academic career, Dr. Selvin has been continually funded as a principal investigator on grants from the National Institutes of Health. Dr. Selvin has a particular interest in the interface of epidemiology and clinical and public health policy. Her work focuses on the study of biomarkers, diagnostics, and technology relevant to diabetes and its complications, including implications for health equity. An overarching goal of her work is to use epidemiologic research to inform diabetes, cardiovascular disease, and kidney disease screening, diagnosis, and treatment.

Pierre Theodore, M.D., is Executive Director of Health Equity at Genentech. In this role, he is responsible to help accelerate innovation, advance the standard of care within early-stage science and to elevate existing and adjacent technologies. Additionally, Dr. Theodore is a Health Sciences Associate Professor of Surgery and holds the Van Auken Endowed Chair in Thoracic Surgery at The University of California, San Francisco School of Medicine. He has over two decades of experience in cardiothoracic surgery, surgical education, entrepreneurship, and innovation. Pierre's practice focused on minimally invasive surgical approaches in thoracic surgery, interventional pulmonary procedures, and Global Surgery initiatives to expand surgical capacity in low-income countries. Pierre has engaged in innovation across a wide range of

domains including health informatics, surgical oncology, and post-surgical rehabilitation. Pierre has founded and served in leadership roles in several start-up companies devoted to health information technology and integrated care and is a co-inventor of several medical devices and drug delivery platforms. Pierre has served as an advisor to numerous venture capital and private equity firms in Silicon Valley, helping to guide strategy in healthcare investments across the digital health, biotech, and medical device sectors. Pierre is a commissioned officer in the United States Navy Reserve Medical Officer Corps, holding the rank of Commander.

Kimani C. Toussaint, Jr., Ph.D., is the Thomas J. Watson, Sr. Professor of Science and Senior Associate Dean for Research and Strategic Initiatives in the School of Engineering at Brown University, and also serves as Director of the Brown-Lifespan Center for Digital Health. Dr. Toussaint also directs the laboratory for Photonics Research of Bio/nano Environments (PROBE Lab), an interdisciplinary research group working in the areas of quantitative nonlinear optical imaging techniques, structured light, nano-optics, and optical health-monitoring techniques that mitigate bias. He is a recipient of a 2010 NSF CAREER Award, the 2014-2015 Dr. Martin Luther King, Jr. Visiting Associate Professor at MIT, the 2015 Illinois Dean's Award for Excellence in Research, the 2017 Illinois Everitt Award for Teaching Excellence, and the 2019 Distinguished Promotion Award. Dr. Toussaint is also a Fellow of Optica (formerly the Optical Society of America), SPIE (Society of Photo-Optical Instrumentation Engineers), AIMBE (American Institute for Medical and Biological Engineering), and AAAS (African Academy of Sciences), as well as a Senior Member in the IEEE (Institute of Electrical and Electronics Engineers). In addition, he is a member of the Board of Reviewing Editors for Science and has served as a Guest Editor for PNAS. Dr. Toussaint is also part of CELL-MET, a multi-institutional National Science Foundation Engineering Research Center in Cellular Metamaterials (EEC-1647837). CELL-MET aims to grow functional and clinically significant heart tissue while simultaneously developing a talented and diverse workforce to tackle future challenges in synthetic tissues engineering. Dr. Toussaint's work on equitable health technologies has appeared in popular press, including NPR, Politico, CNN, STAT+, and the Boston Globe. .

Karen H Wang, M.D., M.H.S., is an Assistant Professor at Yale School of Medicine (General Internal Medicine, Health Informatics), and core faculty at the Yale Equity Research and Innovation Center, SEICHE Center for Health and Justice, and the Center for Community Engagement and Health Equity. Her work is at the intersection of health equity, informatics, and data justice with a focus in optimizing health and health-related information, data, and technology for communities that have been marginalized. Her research goal is to improve the health of communities that have been marginalized by engaging them in the collection and use of health data and improving the quality of social and structural determinants of health data, such as race, ethnicity, and residential address. She leverages a participatory approach to center communities in the design, collection, use of their health data; understand communities' information and technology needs, improve information resources, and accelerate the dissemination of useful data back to communities, from electronic health record data to research study data.

Committee on the Use of Race and Ethnicity in Biomedical Research

January 31, 2024
9:00 AM – 4:30 PM ET

Speaker Guidance Workshop on the Use of Race and Ethnicity in Biomedical Research

BACKGROUND AND CONTEXT

As part of the information gathering phase of their work, [the Committee on the Use of Race and Ethnicity in Biomedical Research](#) would like to learn more about new approaches and alternatives to using race and ethnicity categories. The committee also would like to explore different contexts across the translational research spectrum in which race and ethnicity arise.

SESSION I. HUMAN PHYSICAL VARIATION AND EFFECTS ON HEALTH RESEARCH

Session Objectives

- Learn how human phenotypic variation in skin pigmentation, for example, can be characterized.
- Discuss how variation in traits like skin color and hair contributes to downstream effects in biomedical research.
- Consider new approaches to measure and account for phenotypic variation in research.

Questions for Speakers

1. What is the relationship between phenotypic variation and race and ethnicity categories? How can variation in traits like skin pigmentation and hair be rigorously characterized?
2. How can phenotypic variation contribute to downstream effects in biomedical research?
3. How can researchers better account for variation in traits to improve study design and research outcomes?

SESSION II. ALTERNATIVES TO USING RACE AND ETHNICITY CATEGORIES IN RESEARCH

Session Objectives

- Discuss alternatives to using race and ethnicity categories (e.g., OMB categories) in biomedical research.
- Explore qualitative and quantitative methods for examining race and ethnicity in research.
- Consider advantages and disadvantages of collecting race and ethnicity data.

Questions for Speakers

1. Researchers often rely on categories, such as continental ancestry or the U.S. OMB categories, when designing their studies. What alternatives do researchers have? What are some benefits of these approaches?
2. What are examples of putting these alternative methods into practice? What challenges do researchers face?
3. What are advantages and disadvantages that collecting race and ethnicity data provide?
4. What challenges do legacy data provide when considering race and ethnicity data? Can existing datasets incorporate these newer approaches? How?

SESSION III. RACE AND ETHNICITY IN CLINICAL ALGORITHMS AND TOOLS

Session Objectives

- Examine how race and ethnicity are currently used in clinical algorithms and decision-making tools and discuss the effects of this use.
- Explore whether and how race and ethnicity could be used in the development of future clinical algorithms.

Questions for Speakers

1. How are race and ethnicity categories used in clinical algorithms and tools? What factors should be considered or evaluated to avoid misuse?
2. How can bias be recognized when algorithms or tools do not explicitly include a race variable?
3. How could race and ethnicity, or related variables, be used more appropriately in algorithms and clinical decision-making tools in the future? What changes need to occur to improve their clinical utility and reduce their potential for harm?

4. Are there examples of algorithms and tools currently being used that could be good models for future research in this area?

SESSION IV. INTERSECTION OF RACE AND ETHNICITY IN BIOMEDICAL RESEARCH AND CLINICAL APPLICATIONS

Session Objectives

- Discuss how incorporating race and ethnicity (or not) in early-stage research influences applications in the clinic.
- Explore best practices for collecting patient or research participant information for use in research.

Questions for Speakers

1. What are best practices for collecting patient race and ethnicity information for use in research?
2. How does the incorporation of race and ethnicity data in research affect clinical guidelines and applications?

SESSION V: INDUSTRY PERSPECTIVE ON THE USE OF RACE AND ETHNICITY IN RESEARCH

Session Objectives

- Discuss how regulatory considerations influence collection of race and ethnicity data.
- Explore incentives and disincentives for changing how race and ethnicity data are collected for industry research.

Questions for Speakers

1. What are the unique challenges that industry faces in the use of race and ethnicity in research? How do regulatory considerations affect the collection of race and ethnicity data in industry?
2. How have race and ethnicity been used in industry research in the past? What are the factors that motivate changing industry practices around collecting race and ethnicity data?
3. How could industry and other sectors better collaborate and learn from one another to improve how race and ethnicity are used in research?

Background Materials

Links to Additional Resources

SESSION I: Human Physical Variation and Effects on Health Research

- Jablonski (2021). The evolution of human skin pigmentation involved the interactions of genetic, environmental, and cultural variables.
<https://pubmed.ncbi.nlm.nih.gov/33825328/>
- Jonnalagadda et al. (2016). Association of genetic variants with skin pigmentation phenotype among populations of west Maharashtra, India.
<https://pubmed.ncbi.nlm.nih.gov/26918427/>
- McFarling (2022). 'A poster child' for diversity in science: Black engineers work to fix long-ignored bias in oxygen readings
<https://www.statnews.com/2022/08/19/diversity-in-science-black-engineers-work-to-fix-long-ignored-bias-in-pulse-oximeters/>

SESSION II: Alternatives to Using Race and Ethnicity Categories in Research

- Adkins-Jackson et al. (2023). The Role of Anti-Racist Community-Partnered Praxis in Implementing Restorative Circles Within Marginalized Communities in Southern California During the COVID-19 Pandemic.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9703012/>
- Monk (2023). Which Skin Tone Measures are the Most Inclusive? An Investigation of Skin Tone Measures for Artificial Intelligence.
<https://dl.acm.org/doi/pdf/10.1145/3632120>

SESSION III: Race and Ethnicity in Clinical Data Collection, Algorithms, and Tools

- Banerjee et al. (2022). Reading Race: AI Recognizes Patient's Racial Identity in Medical Images.
<https://arxiv.org/ftp/arxiv/papers/2107/2107.10356.pdf>
- Wang et al. (2020). Information Loss in Harmonizing Granular Race and Ethnicity Data: Descriptive Study of Standards.
<https://pubmed.ncbi.nlm.nih.gov/32706693/>
- Yang et al. (2023). Evaluating the Impact of Social Determinants on Health Prediction in the Intensive Care Unit
<https://arxiv.org/abs/2305.12622>

SESSION IV: Intersection of Race and Ethnicity in Biomedical Research and Clinical Applications

- Brown et al. (2023). Racial and Ethnic Health Disparities in Dermatology.
<https://www.binasss.sa.cr/abr23/21.pdf>
- Carlos (2022). Linking Structural Racism and Discrimination and Breast Cancer Outcomes: A Social Genomics Approach.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC9851699/>

- Selvin et al. (2011). Racial Differences in Glycemic Markers: A Cross-sectional Analysis of Community-Based Data.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3131743/pdf/nihms295038.pdf>

SESSION V: Industry Perspective on the Use of Race and Ethnicity in Research

- Theodore et al. (2015). Implementing an Advanced Thoracic Surgery Program in Rural Haiti: Challenges of High Complexity Surgery in a Low Income Country
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4693915/>