

Improving the Representation of Women and Underrepresented Minorities in Clinical Trials and Research

Committee

Kirsten Bibbins-Domingo

Chair

Kirsten Bibbins-Domingo, PhD, MD, MAS is the Professor and Chair of the Department of Epidemiology and Biostatistics, and the Lee Goldman, MD Endowed Chair and Professor of Medicine at the University of California, San Francisco. She is the inaugural Vice Dean for Population Health and Health Equity in the UCSF School of Medicine. She co-founded the UCSF Center for Vulnerable Populations at Zuckerberg San Francisco General Hospital that focuses on actionable research to increase health equity and reduce health disparities in at-risk communities. She is one of the Principal Investigators for the UCSF Clinical and Translational Sciences Institute, and she leads the newly launched UCSF COVID Community Public Health Initiative. Dr. Bibbins-Domingo is a general internist and cardiovascular epidemiologist whose scholarship includes observational epidemiology, pragmatic trials, and simulation modeling to examine clinical and public health approaches to prevention in the US and globally. She previously served on and led the US Preventive Services Task Force from 2010-2017. She is an inducted member of the American Society for Clinical Investigation, the Association of American Physicians, and the National Academy of Medicine.

Marcella Alsan

Member

Marcella Alsan is a Professor of Public Policy at Harvard Kennedy School. Alsan received a BA from Harvard University (1999), a master's in public health from Harvard School of Public Health (2005), a MD from Loyola University (2005), and a PhD in Economics from Harvard University (2012). Alsan trained at Brigham and Women's Hospital Hiatt Global Health Equity Residency Fellowship – then combined the PhD with an Infectious Disease Fellowship at Massachusetts General Hospital (2013). Prior to returning to Harvard she was on faculty at Stanford. She is an applied microeconomist studying health inequality. Some of her recent papers include “Does Diversity Matter for Health: Experimental Evidence from Oakland” and “Tuskegee and the Health of Black Men” – published in the American Economic Review and The Quarterly Journal of Economics, respectively. These papers have been cited in the New York Times and other major media outlets and findings have been presented to the Association of American Medical Colleges and the Centers for Disease Control and Prevention. She is currently on the Board of Editors for Science Magazine, Co-Editor of the Journal of Health Economics and Co-Chair of the Health Care Delivery Initiative of Poverty Action Lab based out of MIT. She is the co-recipient of the 2019 Arrow Award for Best Paper in Health Economics.

Arleen F. Brown

Member

Arleen Brown, MD, PhD, Professor of Medicine at UCLA and Chief of General Internal Medicine and Health Services Research at Olive View-UCLA Medical Center, is a primary care provider and researcher with expertise in chronic disease disparities and community engaged research. She has focused on health care system, social, and individual level determinants of health for persons with diabetes, hypertension, and other risk factors for cardiovascular disease and stroke. Dr. Brown also co-leads the Community Engagement and Research Program of the UCLA Clinical and Translational Science Institute. Her current projects include two NIH-funded community-partnered projects. “Share, Trust, Organize, Partner: the COVID-19 California Alliance” (STOP COVID-19 CA) is a coalition of 11 academic institutions and their network of community partners, working collaboratively to address racial/ethnic and socioeconomic disparities in COVID-19 risk and outcomes across the state. She also leads an NIH-funded project to reduce hypertension disparities in the health care safety net using culturally tailored, community-engaged methods.

Gloria D. Coronado

Member

Gloria Coronado, PhD, is an epidemiologist and the Mitch Greenlick Endowed Distinguished Investigator in Health Disparities Research at Kaiser Permanente Center for Health Research. She completed her training at Stanford University (BA 1994, Psychology) and the University of Washington (MS 1998, PhD 2001, Epidemiology). Through her practice-based research, Dr. Coronado champions affordable, long-term solutions to health disparities issues. She leads a well-funded portfolio of research that inspires health system leaders to make sensible, evidence-informed choices to successfully engage hard-to-reach populations in life-saving preventive behaviors. Dr. Coronado has developed several innovative and cost-effective interventions to improve rates of participation in cancer screening among patients served by community health centers. Her innovative work has led to successful partnerships with large health plans, state institutions, and community clinics. She currently directs or co-directs three programs that use systems-based approaches to raise the rates of colorectal cancer screening and follow-up care in health plans and clinics in Washington, Oregon and California. Over the course of her career, Dr. Coronado has served as a PI or co-I on over 35 federally funded grants; she has co-authored over 170 peer-reviewed manuscripts. She currently serves as a Steering Committee member of the National Colorectal Cancer Roundtable.

Carlos del Rio

Member

Dr. Carlos del Rio is a Distinguished Professor of Medicine at Emory University School of Medicine and Professor of Epidemiology and Global Health at the Rollins School of Public Health of Emory University. He is also the Executive Associate Dean for Emory University School of Medicine at the Grady Health System. Dr. del Rio is PI and co-Director of the Emory Center for AIDS Research as well as co-PI of the Emory-CDC HIV Clinical Trials Unit and the Emory Vaccine and Treatment Evaluation Unit. He has significant experience in the conduct of clinical trials including a track record of recruiting woman and underrepresented populations into studies. Dr. del Rio was elected as Foreign Secretary of the National Academy of Medicine in 2020.

XinQi Dong

Member

Dr. XinQi Dong is the Director of the Institute for Health, Health Care Policy, and Aging Research (IFH) at Rutgers University as well as the inaugural Henry Rutgers Professor of Population Health Sciences. Dr. Dong has published extensively on the topics of violence prevention in global populations and is the PI of multiple federally-funded grants including NIA funded P30 Center: Resource Center for Minority Aging Research (RCMAR). Dr. Dong edited the key textbook on elder abuse - the field's largest collection of research, practice, and policy. Dr. Dong is the recipient of multiple national and international awards. He served as senior advisory to DHHS during the Obama Administration as well as commissioner for American Bar Association. Within NAM/IOM, Dr. Dong has served in multiple capacities as members of the IOM Global Violence Prevention Forum and of the NAM Consensus Panel/Planning Committee for the Committee on Care interventions for Individuals with Dementia and their Caregivers. An immigrant to the United States, Dr. Dong grew up in a rural village near Nanjing, China. He received his BA in biology and economics from the University of Chicago in 1994, his MD at Rush University College of Medicine 1999, and his MPH in epidemiology at University of Illinois at Chicago. He completed his internal medicine residency and geriatric fellowship at Yale University Medical Center.

Dana P. Goldman

Member

Dana Goldman has served on several National Academies committees and has written on the costs of conducting clinical trials and policies to enhance their representativeness. He is the Interim Dean of the USC Sol Price School of Public Policy, where he holds the Leonard D. Schaeffer Director's Chair and is a Distinguished Professor of Public Policy, Pharmacy, and Economics. Since its founding, Dr. Goldman has led the USC Schaeffer Center for Health Policy & Economics, one of the nation's premier health policy programs. He is an elected member of the National Academy of Medicine and the National Academy of Social Insurance. He is the author of more than 300 articles, and his research has been published in leading medical, economic, health policy, and statistics journals and other media. He has raised over \$100 million in support of health policy research—including \$50 million from the NIH. He has served or is serving as a health policy advisor to the Congressional Budget Office, Covered California, NIH, the Fred Hutchinson Cancer Institute, and several life sciences companies. Dr. Goldman is a member of the editorial boards of Health Affairs and the American Journal of Managed Care and was founding editor of the Forum for Health Economics and Policy. His work has been featured in the New York Times, Wall Street Journal, Washington Post, The Economist, NBC Nightly News and other media. He is a former director of ISPOR and ASHEcon. Dr. Goldman received his B.A. summa cum laude from Cornell University and a Ph.D. in Economics from Stanford University.

Sharon K. Inouye

Member

Sharon K. Inouye, M.D., MPH is Professor of Medicine, Harvard Medical School, Milton and Shirley F. Levy Family Chair, and Director, Aging Brain Center, Marcus Institute for Aging Research, Hebrew SeniorLife. Dr. Inouye is an internationally recognized leader in aging, public health, epidemiology, clinical trials, health equity, and health policy. As a geriatrician, she maintains a clinical practice in geriatric and homeless populations, and currently mentors over 20 early stage investigators. She received her BA (1977, English Literature) from Pomona College; MD (1981) from UCSF School of Medicine; and MPH (1989) from Yale School of Public Health. She has served as a Health and Aging Policy Fellow (2016-2017) and American Political Science Association Congressional Fellow (2016-2017) and an Encore Public Voices Fellow (2019-2020). She is an elected member of the National Academy of Medicine (2011), who has served on the IOM Committee on Cognitive Aging, and the NAM Membership and Nominating Committees. She currently participates in the NASEM Health Care Services Board and NAM/APHA's Covid19Conversations.org Advisory Board, serves as a member of the President's Advisory Panel and Steering Committee for NAM's Healthy Longevity Roadmap Project, and served as former Chair of the NAM Interest Group on the Biology of Aging and Geriatrics (IG10), and Co-Chair of the Workshop on Health Care Systems and Public Health for Healthy Longevity for the NAM. Throughout the pandemic, Dr. Inouye has brought attention to vulnerable populations, including those based on age, race, socioeconomic status, disability, and homelessness, with many pertinent articles in biomedical journals (NEJM, Age & Aging), as well as the New York Times, NPR, BBC, and others related to equity issues surrounding COVID-19 treatment, enrollment into vaccine trials, equitable allocation of critical care resources, and other pressing issues.

Amelia S. Knopf

Member

Dr. Amelia Knopf is an Assistant Professor of Nursing at Indiana University. She earned her Bachelor of Science in Nursing from Western Kentucky University in 2000; after graduation she was awarded a fellowship in Oncology Clinical Trials at the National Institutes of Health Warren Grant Magnuson Center, where she administered Phase IIa therapies to patients enrolled in oncology clinical trials. After noting significant underrepresentation of marginalized populations in clinical trials, she took a position as a primary care nurse for homeless and justice-involved adults in Washington, DC to better engage in the health care of marginalized persons. She subsequently attended the University of Washington where she earned a Master of Public Health (2008) and a PhD in Nursing Science with Special Emphasis in Statistics (2013). In her first five years on the IU faculty, she has secured \$2.6 million in external funding as a PI or co-investigator for research focused on engaging marginalized populations in clinical trials for sensitive and stigmatizing health problems, such as HIV. She has successfully enrolled minor adolescents, racial and ethnic minorities, justice-involved populations, and sexual and gender minorities in her research studies. She is co-chair of the Adolescent Medicine Trials Network for HIV Interventions (ATN) Bioethics Working Group; her work has informed the World Health Organization's international guidelines for sexual and reproductive health interventions and has been cited by the U.S. Food and Drug Administration, U.S. Centers for Disease Control and Prevention, U.S. Department of State, the NIH Clinical Center Department of Bioethics, and the National Institute for Child Health and Human Development. Dr. Knopf was recently inducted as a Fellow in the American Academy of Nursing and was awarded a visiting residency in bioethics at the Brocher Foundation in Hermance, France in 2020.

Edith A. Perez

Member

Edith A. Perez, MD is an internationally recognized translational researcher and cancer specialist, Chief Medical Officer of Bolt Therapeutics, Inc., Professor of Medicine at Mayo Clinic, and Director of the Mayo Clinic Breast Cancer Translational Genomics Program. Dr. Perez is known for her strategic vision in designing innovative clinical trials, her passion for patient care, and her strong team leadership. Her experience includes leadership in academic and biopharmaceutical environments, as well as focused philanthropic endeavors. Her academic work has been extensive, including chairing the NCCTG Breast Committee, serving in multiple committees with the NCI (such as the Board of Scientific Advisors, Clinical Trials and Translational Advisory Committee, amongst others), grant reviewer for the NIH, extensive editorial board and reviewer for multiple journals, participation, and leadership in Independent Data Monitoring Committees, leading the Publication Committee for the Alliance for Clinical Trials in Oncology, membership in Institute of Medicine Committees including the most recent one Use of Biomarkers for Selection of Molecularly Targeted Therapies. Dr. Perez earned her medical degree from the University of Puerto Rico School of Medicine in San Juan and completed her residency in internal medicine at the Loma Linda University Medical Center in California. She served as a general internist in the Division of National Health Services Corps, LA, and completed her Hematology/Oncology fellowship at the University of California, Davis School of Medicine. Dr. Perez also pursued additional leadership, management, and executive development at The Wharton School of the University of Pennsylvania and Harvard Kennedy School in Boston. Dr. Perez is board certified in internal medicine, medical oncology, and hematology.

Phyllis J. Pettit Nassi

Member

Phyllis Pettit Nassi, MSW, BS, is enrolled in the Otoe-Missouri Tribe & a member of the Cherokee Nation, and is the Associate Director Research & Science, Special Populations, American Indian Program at Huntsman Cancer Institute, University of Utah. Phyllis is experienced in scientific research, outreach, development & implementation of research projects and is well aware of the need for cultural humility & awareness & works with research teams to understand "how complicated it's going to be to get it right," & how difficult it will be for every researcher working with Native American people if they get it wrong. Her interest is the health disparities of the medically underserved of rural & frontier populations, providing cancer research education with the goal of bringing equity to the research table & the importance of participating in clinical trials and of screening & early detection. She has studied cultural & social implications of underserved populations for more than 30 years; formerly a Ph.D. student at the University of Utah's College of Social Work, Phyllis received a Masters of Social Work in 2006, with a research emphasis in health disparities of the medically underserved and rural & frontier populations. She is a member of Subcommittee A - Cancer Centers National Cancer Institute Initial Review Group, a member of the American Association for Cancer Researchers, an Alliance for Clinical Trials in Oncology Patient Advocate serving on the Patient Advocate, Health Disparities & Pharmacogenetics & Population Pharmacology Committees, an Advocate in Science member for Susan G. Komen for the Cure and Co-Chair of the Southwest Region of the Intercultural Cancer Council Network. Phyllis has been invited to participate at the National Academies of Sciences Engineering Medicine, Health and Medicine Division, Roundtable on Health Literacy in Clinical Trials: Practice and Impact 2019 Workshop as the moderator for Incorporating Health Literacy Principles into Clinical Trials and as a Cultural Influences on Trust in Science presenter at the National Academies of Sciences Engineering Medicine, Division of Behavioral and Social Sciences and Education, Roundtable on Public Interfaces "Does the Public Trust Science? Trust and Confidence at the Intersections of the Life Sciences and Society" Workshop in 2015.

Jason Resendez

Member

Jason Resendez currently serves as the Executive Director of the UsAgainstAlzheimer's Center for Brain Health Equity—partially funded by the Centers for Disease Control and Prevention's (CDC) Healthy Brain Initiative—which focuses on advancing health equity in brain health education and research. In 2020, Resendez was recognized as one of America's top 20 "Influencers in Aging" by PBS Next Avenue. Jason has helped establish UsAgainstAlzheimer's as a hub for driving health equity in brain research and care through patient-centered public health strategies and research collaborations in partnership with academic medical centers, industry leaders, and community-based organizations serving multicultural communities. From 2016 to 2018, he was a co-principal investigator with Dr. Goldie Byrd, Professor of Public Health Sciences at Wake Forest, on a Patient Centered Outcomes Research Institute (PCORI) Patient Engagement Award to establish the Alzheimer's Disease Disparities Engagement Network, a platform for connecting researchers, patients, caregivers and community leaders to share insights and establish collaborative partnerships to address disparities in Alzheimer's research engagement. Jason is currently a co-principal investigator of the Foundations of Representative Engagement, Valid & Effective Recruitment in Alzheimer's Research study (FOREVER) (NIH/NIA- 1DP1AG069873-01) with Dr. Jonathan Jackson of Massachusetts General Hospital. The project will operationalize the science of engagement, recruitment, and retention by developing a data-based framework directed at, and informed by, lay communities, research communities, and their intersection.

Susan Schaeffer

Member

Susan Schaeffer (President and CEO) founded The Patients' Academy for Research Advocacy after spending 15 years at BioCentury informing and educating biopharma industry stakeholders on best practices and innovation in clinical development, regulation, pricing and market access. Although not a scientist by training, in 2002 she dedicated her career to learning about and improving drug development after the loss of a close friend to breast cancer at a very early age. She joined the biopharmaceutical industry journal BioCentury as a staff writer in 2003, with no background in science or the biopharmaceutical industry, learning about the business and science of developing drugs by interviewing CEOs and scientists about their work. She became managing editor of BioCentury and the daily news digest BioCentury Extra in 2004, led BioCentury's Product Discovery & Development coverage as senior editor from 2010 through 2012, and took the helm of the publication in 2012. As head editor, Susan became an early champion of patient-centered R&D as an essential practice for translating great science into medicines that patients really want and society will pay for. Susan is a member of NASEM's Forum on Drug Discovery, Development & Translation and co-chairs the Community Engagement Working Group of the North American Spinal Cord Injury Consortium. She obtained a B.F.A. in painting from the San Francisco Art Institute in 1991.

Alex Helman

Staff Officer