

Mridul Gautam, Ph.D.
Vice President for Research and
Innovation
Professor of Mechanical
Engineering
University of Nevada, Reno

Welcome Address

As vice president for research and innovation and professor of mechanical engineering at the University of Nevada, Reno, Dr. Mridul Gautam leads the articulation and implementation of a shared vision for research and guides the administrative division focused on developing world-class research and discovery, the careers and competitiveness of faculty, and the institution's capacity as a high-impact research university and economic cornerstone of Nevada. Dr. Gautam also serves as President of the Nevada Research and Innovation Corporation. Prior to joining the University in 2013, he served as associate vice president for research at West Virginia University (WVU) as well as the vice president for the WVU Research Corporation.

Under his leadership, Research & Innovation provides the highest quality of services and infrastructure to enable faculty, students and staff to excel in their research, scholarly and creative endeavors and to advance innovation and commercialization. The division helps build interdisciplinary collaborations, assist researchers in obtaining and managing extramural funding, and maintain a safe, healthy and ethical environment in which to conduct research. The division is committed to facilitating connections with industry and fostering regional entrepreneurship and collaboration through an innovative ecosystem, anchored by the Nevada Center for Applied Research and the University of Nevada, Reno Innevation Center—Powered By Switch.

Dr. Gautam is a Fellow of the National Academy of Public Administration. He serves on several national committees including the Association of Public and Land-Grant Universities' Council on Research Executive Committee and its Research Task Force on Laboratory Safety, Board of Directors of the University Economic Development Association, Board of Directors and Executive Committee of the Coalition of EPSCoR/IDeA States, and Board of Directors of the Desert Research Institute Research Park, and he is a member of the National Academies' Government-University-Industry Research Roundtable. As a member of the University's President's Council, Dr. Gautam advises on major policy issues and addresses state and national issues of compelling interest to the University's research community. Dr. Gautam is an internationally recognized researcher and expert in the area of heavy-duty mobile source exhaust emissions, aerosol sampling, and particulate matter measurement, characterization, and control. He has over 27 years of experience in initiating and managing large interdisciplinary and multi-institutional programs and has served as a principal investigator and/or co-principal investigator on over \$80 million in funded research. Dr. Gautam has published more than 400 technical articles including refereed journal articles, symposia/published proceedings and published abstracts of papers presented at professional meetings. In addition to having a licensing agreement to his credit, he is a recipient of the Outstanding Aerosol Paper Award through the American Industrial Hygiene Association and the American Conference of Governmental Industrial Hygienists, the Ralph R. Teetor Educational Award through the Society of Automotive Engineers, and several Outstanding Researcher of the Year awards at WVU.

Dr. Gautam received his doctorate in mechanical engineering from West Virginia University in 1989 and his master's in mechanical engineering from the Indian Institute of Technology, Delhi in 1984.



Jessica Ridpath
Communications
Manager
Kaiser Permanente
Washington Health
Research Institute

Using Plain Language in Informed Consent Documents

Jessica Ridpath is a writer and editor specializing in plain language communication in health care and health research. She serves as Kaiser Permanente Washington Health Research Institute (KPWHRI)'s lead editor for study recruitment materials (advance letters, information sheets, consent forms, study brochures, recruitment flyers, etc.) and other print materials for study participants (intervention materials, study results letters, etc.). In addition, Jessica leads KPWHRI's Program for Readability In Science & Medicine (PRISM), a plain language initiative she founded in 2005. PRISM's mission is to bring plain language tools and training to health care researchers nationwide. Through PRISM, she has provided plain language training and editing to a broad range of clients, including hospitals, public health departments, and organizations such as Fred Hutchinson Cancer Research Center, Program for Appropriate Technology in Health (PATH), and the National Cancer Institute. Jessica has also developed two widely used, public-domain resources to support the use of

plain language in research: the <u>PRISM Readability Toolkit</u> and a Web-based training course freely available at https://prism.kpwashingtonresearch.org/. Jessica has a bachelor's degree in women studies from The Colorado College.

KEYNOTE: Research in the Digital Age: Promises and Perils from an Ethics Lens

Camille Nebeker is an Associate Professor of Behavioral Medicine in the Department of Family Medicine & Public Health, School of Medicine, UC San Diego. Her research and teaching focus on two intersecting area: 1- community research capacity building (e.g., citizen science and community engaged research) and, 2- digital health research ethics (e.g., consent, privacy expectations, data management). She directs the new Research Center for Optimal Digital Ethics (ReCODE.Health) and is core faculty with the UCSD Design Lab and Center for Wireless and Population Health Systems. She leads the Building Research Integrity and Capacity BRIC programs and the Connected and Open Research Ethics CORE initiative. Dr. Nebeker's research has received continuous support from government, foundation and industry sources since 2002. Dr. Nebeker is core faculty with the UC San Diego Design Lab and the Center for Wireless and Population Health Systems.



Camille Nebeker, EdD, MS

Director, Research Center for

Optimal Digital Ethics
(ReCODE.Health)

Associate Professor of
Behavioral Medicine,
Department of Family Medicine
and Public Health, School of
Medicine
UC San Diego



John Wilbanks Chief Commons Officer Sage Bionetworks

PLENARY 1: Mobile Technology and Informed Consent

John Wilbanks is the Chief Commons Officer at Sage Bionetworks. Previously, Wilbanks worked as a legislative aide to Congressman Fortney "Pete" Stark, served as the first assistant director at Harvard's Berkman Center for Internet & Society, founded and led to acquisition the bioinformatics company Incellico, Inc., and was executive director of the Science Commons project at Creative Commons. In February 2013, in response to a We the People petition that was spearheaded by Wilbanks and signed by 65,000 people, the U.S. government announced a plan to open up taxpayer-funded research data and make it available for free. Wilbanks holds a B.A. in philosophy from Tulane University and also studied modern letters at the Sorbonne.

PLENARY 2: Trust Development as an Ethical Research Process

Julie Lucero, MPH PhD, is an assistant professor in the School of Community Health Sciences and Director of the Latino Research Center at the University of Nevada, Reno. Using mixed methods and community based participatory research (CBPR), Dr. Lucero has been involved with CBPR projects in collaboration with American Indian, Hispanic, and LGBT communities that center on the identification of modifiable social determinants to achieve health equity within underrepresented populations. These projects examined factors associated with substance abuse, mental health, positive youth development, and health service utilization. In a current project, she explores the role of trust in promoting effective processes and outcomes in community-academic partnerships. Previous research found various communication ethics to be trust antecedents and significantly associated with power relations, sustainability, and overall research outcomes. Furthermore, trust, governance and culture were



Julie E. Lucero, MPH, PhD
Director, University of Nevada
Reno Latino Research Center
Assistant Professor, School of
Community Health Sciences
University of Nevada, Reno

found to be significant cross-cutting themes (pillars) associated with a variety of outcomes throughout the partnering and research process. Acknowledging the fragile nature of trust, future research will identify concepts and constructs associated with change in trust over partnership lifespans.



George GasparisPresident, The PEER
Consulting Group

BREAKOUT SESSION 1a: Current Challenges from the Implementation of New Regulations and Standards for Human Subjects Protection

George Gasparis has over 35 years of experience in the administration or conduct of human subjects research. Prior to founding "PEER", he served as the Asst. VP and Sr. Asst. Dean for Research Ethics at Columbia University (CU), CU Medical Center (CUMC) from 2003-12, where he directed the IRB Office and compliance team. He worked at the Office for Human Research Protections (OHRP) for seven years and served as the Director, Division of Assurances and Quality Improvement from 2000-03, where he led the development of the OHRP QI Program and electronic submission of the Federalwide Assurance (FWA). He has also served as the Director, The George Washington University Medical Center (GWUMC) IRB and Research Pharmacy after serving as a Data Manager for over 40 clinical trials at GWUMC.

BREAKOUT SESSION 2a: Wearable Technology in Physical Activity Research

Dr. Ya-Wen (Janice) Hsu received her B.S. in public health from the National Taiwan University in Taiwan, later she went to the University of Southern California earned her MPH in health communication and her Ph.D. in preventive medicine with a focus on health behavior. Her research focused on obesity prevention and behavioral epidemiology, specifically my work aims at reducing weight-related chronic disease risks (e.g. obesity, diabetes, cardiovascular disease, and stroke) through promoting healthy behaviors (e.g. physical activity, sleep, and diet). She is particularly concerned with understanding how behavioral, psychosocial, metabolic, and social forces interact to influence behavior and health. Her recent research project is about how to use mobile technology and "nudge" to change physical activity behavior.



Ya-Wen Hsu, PhDAssistant Professor, School of
Community Health Sciences
University of Nevada, Reno

BREAKOUT SESSION 2a: Privacy Concerns in the Collection of First-person Video

Mark Lescroart joined the Cognitive & Brain Sciences group in the department of psychology at the University of Nevada, Reno in the spring of 2018. He got his Ph.D. at the University of Southern California working with Irving Biederman and did postdoctoral research with Jack Gallant at UC Berkeley. The goal of Dr. Lescroart's lab is to understand how our brains transform patterns of light on our retinas into useful information about the world; specifically, how different areas in the brain provide information about the identity and shape of objects, the structure of space, and the types of actions (such as running, jumping, and throwing) performed by humans around us. Dr. Lescroart pursues these questions by making computational models of brain responses measured by fMRI while



Mark D. Lescroart, PhD
Assistant Professor of
Psychology, Cognitive and
Brain Sciences
University of Nevada, Reno

people perform different tasks. These models can then be used to reconstruct the images or tasks that elicited a particular brain response. This is the most concrete way Dr. Lescroart has found to explore what ideas look like.



Paul MacNeilage, PhD
Assistant Professor of
Psychology, Cognitive and
Brain Sciences
University of Nevada, Reno

BREAKOUT SESSION 2a: Privacy Concerns in the Collection of First-person Video

Paul MacNeilage is the leader of the Self-motion Laboratory where he investigates how the nervous system reconstructs head and body motion through space based on both sensory and motor signals. He has an undergraduate degree in Biological Anthropology from Harvard University and a PhD in Vision Science from UC Berkeley. From 2010 to 2016 he was the leader of a research group at the German Center for Vertigo at the University Hospital of Munich. Since 2017, he has been Assistant Professor of Psychology in the Cognitive and Brain Sciences program at the University of Nevada, Reno.

BREAKOUT SESSION 3a: Assessing Capacity to Consent for Research with Older Adults

Esther Lara is currently Clinical Research Administrator and Clinical Social Worker of the UC Davis Alzheimer's Disease Center in the department of Neurology at UC Davis.

For the last 27 years she has been working in clinical research with older adults, people experiencing cognitive impairments and Alzheimer's disease and related dementias. Her focus is inclusion of Latinos, African Americans and people with lower levels of educational attainment in clinical research. She has over 27 year of clinical experience working with family caregivers.



Esther Lara, MSW

Clinical Social Worker & Clinical
Research Administrator,
Alzheimer's Disease Center
UC Davis



David Heagerty, CIPAssociate Director, IRB
University of Pennsylvania

BREAKOUT SESSION 1b: Broad Consent: An Alternative Perspective

Dave Heagerty is the Associate Director of the University of Pennsylvania Human Research Protection Program. Dave is responsible for IRB operations including management of the 9 IRBs at Penn and was involved in updating Penn's policies to align with the new Final Rule. Dave's particular interest include social and behavioral research, conflict of interest, HIPAA in research, and research with big data.

BREAKOUT SESSION 1b: Broad Consent: An Alternative Perspective

Jessica Yoos is the Assistant Director of the Institutional Review Board at the University of Pennsylvania with expertise in U.S. Food and Drug Administration (FDA) drug and device regulations, research design, and statistical analysis. Her research interests include the ethical review and conduct of pragmatic clinical trials, construction and validation of assessments and scales, the ethical review of statistical plans, and improving the efficiency and objectivity of IRB review. Jessica has a Master's Degree in Clinical Psychology from



Jessica L. Yoos, MA, CIP
Assistant Director, Institutional
Review Board
University of Pennsylvania

Columbia University and will graduate in May 2020 with a Master's Degree in Quantitative Methods from the University of Pennsylvania.



Katherine Kim, PhD, MPH, MBA

Assistant Professor,
University of California,
Davis
Director, Person-Centered
Health Innovation Research
in the UC Davis Center for
Health & Technology and
Senior Scientist for Health at
CITRIS (Center for
Information Technology
Research in the Interest of
Society)

BREAKOUT SESSION 2b: Participatory Research in the Age of Digital Health

Dr. Katherine Kim is Assistant Professor at the University of California Davis in the Betty Irene Moore School of Nursing and the School of Medicine, Public Health Services Department-Health Informatics Division. She serves as the Director of Person-Centered Health Innovation Research in the UC Davis Center for Health & Technology and Senior Scientist for Health at CITRIS (Center for Information Technology Research in the Interest of Society), a state innovation center housed at University of California Berkeley. She is a member of the core team leading the Healthy Aging in a Digital World "Big Idea" at UC Davis.

Dr. Kim is a health informatics researcher specializing in technology-enabled health care for cancer, heart failure, other chronic conditions. Dr. Kim's research focuses on engagement of patients, communities, and healthcare teams in use of mobile health and predictive analysis models for precision health. She also serves on the leadership team of pSCANNER: Patient-centered SCAlable National Network for Effectiveness Research, a stakeholder-governed, clinical data research network covering 34 million patients, and the California consortium of the national All of Us: Precision Medicine Initiative Research Program which seeks for create a one million person national cohort for data-driven health as unique as every individual.

Dr. Kim has over 20 years of previous experience as a hospital and medical group manager, an entrepreneur--CEO of a venture-funded startup, leader of a technology incubator, and founder of a consulting firm—and in software product development with Oracle. She received a PhD at UC Davis, MPH/MBA at UC Berkeley, and BA at Harvard.

BREAKOUT SESSION 3b: Undocumented Migrant Youth and Families in Crisis

Deborah A. Boehm is Professor of Anthropology and Gender, Race, and Identity at the University of Nevada, Reno. During 2019-2020, she is a Mellon/ACLS Scholars & Society Fellow in residency at Freedom for Immigrants. She is the author of *Intimate Migrations*: Gender, Family, and Illegality among Transnational Mexicans and Returned: Going and Coming in an Age of Deportation, and co-editor of Illegal Encounters: The Effect of Detention and Deportation on Young People and Everyday Ruptures: Children, Youth, and Migration in Global Perspective. Her research has been supported through a Fulbright-García Robles Award and an American Council of Learned Societies Fellowship, as well as residencies at the School for Advanced Research, the University of Arizona School of Anthropology, and the Center for the Study of Law and Society at the University of California, Berkeley School of Law. Her current research projects focus on U.S. immigration detention regimes and the experiences of young people who migrate to the United States.



Deborah A. Boehm, PhD
Mellon/ACLS Scholars &
Society Fellow 2019-2020
Professor, Anthropology and
Gender, Race, and Identity,
University of Nevada, Reno



Benjamin A. Mooso, MS, CCRP Associate Director, IRB Administration University of California, Davis

BREAKOUT SESSION 1c: Implementing the Single IRB Provision of the Revised Common Rule: Tips and Potential Pitfalls

Benjamin Mooso currently serves as the Associate Director for IRB Administration at the University of California, Davis. He received his Bachelor's degree from the University of California, Davis in Biochemistry and Molecular Biology and his Master's degree from California State University, Sacramento in Biological Sciences with an emphasis in Cell and Molecular Biology. Benjamin began his career as a basic and translational researcher working in the field of genitourinary cancers. From there he moved into research administration and human subjects protections working with IRBs and clinical researchers to ensure proper regulatory oversight of a broad range of studies.



Rob Romanchuk, BSHS, CIP, CCRC, CRCP Chairperson, Advarra

BREAKOUT SESSION 2c: Mobile Apps: Privacy and Confidentiality in the Age of Mobile Apps and Connected Devices

Rob Romanchuk is a clinical research professional with over 2 decades of experience in research operations and human subjects protections. After spending 15 years building and managing a central research office for a large mutli-hospital community health system, he went on to work as IRB member and Chair for a large independent IRB where he also specializes in medical device research reviews. He speaks widely on topics ranging from contract and budget negotiation to the protection of vulnerable subjects. He has a BSHS in Clinical Research Administration and has certifications as CCRC, CIP and CRCP.