

Breakout Session on "Making Controlled-Access Data Readily Findable and Accessible"

*July 22, 3 to 5:30 p.m.*

**Panelist Biographies**



**J. Michael Gaziano, MD, MPH**

Executive Director of the Massachusetts Veterans Epidemiology Research and Information Center (MAVERIC), VA Boston Healthcare System; Chief, Division of Aging, Brigham and Women's Hospital; Professor of Medicine, Harvard Medical School

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Dr. Gaziano is a preventive cardiologist and internationally recognized chronic disease epidemiologist whose research interests include the epidemiology of chronic diseases using large data sources. He has a particular interest in the lifestyle, metabolic, biochemical and genetic determinants of common chronic disease such as cardiovascular disease and cancer.

A centerpiece of his research involves the conduct of observational studies and trials that are imbedded in a health care system and the curation of electronic health data from many sources. He serves the Director of the CSP Epidemiology Center at MAVERIC and as one of two PIs of the Million Veteran Program (MVP), a project that will enroll one million veterans into a longitudinal cohort with stored biospecimens, self-reported data and the rich electronic clinical and administrative data available in the VA. To date over 850,000 veterans have been enrolled into MVP. He is involved a new initiative in health data science that combines the health data of the VA including data on about 24 million users of the Veterans Healthcare System over the last 2 decades with the computing power and expertise in the Department of Energy. He is principal investigator of the Physicians' Health Study, a large-scale trial-based cohort of over 29,000 physicians followed for over 35 years. He has also served as PI, Co-PI or co-investigator on a number of other cohort studies and large-scale trials. He serves on the advisory committee for UKBiobank.

Dr. Gaziano oversees several fellowship programs and teaches advanced epidemiology at the Harvard School of Public Health. He has published over 700 journal articles, reviews, book chapters and books. He served as an Associate Editor for the Journal of the American Medical Association. He is a Fellow of the Royal College of Physicians.



**Kerry Goetz, MS**

*Associate Director, National Eye Institute, Office of Data Science and Health Informatics*

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Kerry Goetz is the Associate Director for the National Eye Institute's Office of Data Science and Health Informatics. In this capacity she is responsible for advancing data management and sharing strategies to make NEI data FAIR (Fully AI-Ready & Findable, Accessible, Interoperable, and Reusable). For over a decade, Kerry has been leading the eyeGENE Program, a controlled access resource with data, samples, and a patient registry for rare eye conditions. She has implemented sharing of several other clinical trial datasets through NEI BRICS, part of the NEI Data Commons. Kerry has also been entrenched in standards development through the NIH CDE Task Force since 2011 and has worked closely with LOINC to create and review ophthalmology codes.



**Stan Ahalt, PhD**

Director, Renaissance Computing Institute (RENCI), UNC-Chapel Hill

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Dr. Stan Ahalt is the Director of the Renaissance Computing Institute (RENCI) at UNC-Chapel Hill. As Director, he leads a team of research scientists, software and network engineers, data science specialists, and visualization experts who work closely with faculty research teams at UNC, Duke, and NC State as well as with partners across the country. Dr. Ahalt is also a Professor in the UNC Computer Science Department and the Associate Director of the Informatics and Data Science (IDSci) Service in the North Carolina Translational and Clinical Sciences Institute (NC TraCS), UNC's CTSA award. Additionally, Dr. Ahalt is PI for the NHLBI BioData Catalyst Coordinating Center, which manages and unifies the diverse teams working on BioData Catalyst; the BioData Catalyst project aims to develop a groundbreaking instance of a Commons, particularized for the purposes of NHLBI. Furthermore, in his PI role on the NCATS Biomedical Data Translator project, he leads the Exposures Provider Team to best leverage RENCi's, TraCS', and UNC's resources and expertise toward completion of the goal to build architecture and test the feasibility of the Translator. Dr. Ahalt also serves as PI for the NIH HEAL Initiative project, "A Strategy for a HEAL Federated Data Ecosystem," for which he leads the HEAL Data Stewardship Group. The HEAL Ecosystem will be a vital resource that allows researchers to search, access, share, and compute across diverse HEAL data to accelerate scientific solutions to the national opioid crisis. Within this ecosystem, the HEAL Data Stewardship Group (HEAL Stewards) functions as a core resource to ensure that HEAL data is shareable, findable, usable, and valid.

**Lucy Hsu**

*Program Official*, National Heart, Lung, and Blood Institute, National Institutes of Health

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Lucy Hsu serves as a Program Official for grants (i.e., [IDEA2Health](#)) and the Data Repository Program Officer for the [BioLINCC](#) Program (<https://biolincc.nhlbi.nih.gov/home/>), one of the Data Repository entities at the National Heart, Lung, and Blood Institute (NHLBI), NIH. Her training is in biostatistics. She joined the NHLBI in 2011. Prior to joining the NHLBI, she had more than 20 years of work experience in the biomedical field, including advanced statistical analyses with various types of data (i.e., disease surveillance, electronic health/medical records, healthcare claims, real world data, etc.); study designs (i.e., observational, environmental, epidemiological, pharmacoepidemiologic, and experimental studies, clinical trials, complex-design surveys, etc.); and data management.



**Ramona Walls, Ph.D.**

*Associate Director of Data Science, Critical Path Institute*

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Ramona Walls received a bachelor's degree in Environmental Resource Management and Horticulture at Penn State, a Ph.D. in Ecology and Evolution from Stony Brook University, and was a post-doctoral researcher in informatics at the New York Botanical Garden. In December 2020, Walls joined the Critical Path Institute as a Data Scientist specializing in semantics, ontologies, and metadata. She is currently leading data integration effort for the Rare Disease Cures Accelerator Data and Analytics Platform (RDCA-DAP). Walls is also an Assistant Research Professor in the Bio5 Institute at the University of Arizona, where her research focuses on ontology design, ontology-based data integration, and management of large and dispersed datasets, with a focus on biodiversity and environmental data. Her current projects include the NSF-funded iSamples, which is a multi-disciplinary and multi-institutional project to design, develop, and promote service infrastructure to uniquely identify material samples, record metadata about them, and persistently link them to other samples and derived digital content, including images, data, and publications. Walls is a board member and active contributor to the Genomics Standards Consortium. She is a founding member of the OBO Foundry Operations Committee and has contributed to many OBO ontologies.

Google scholar profile: <https://scholar.google.com/citations?hl=en&user=rEhRmsYAAAAJ>



**Melissa Haendel, Ph.D.**

*Chief Research Informatics Officer* at the University of Colorado Anschutz Medical Campus, and Director of the Center for Data to Health (CD2H)

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Dr. Haendel is the Chief Research Informatics Officer at the University of Colorado Anschutz Medical Campus, and Director of the Center for Data to Health (CD2H). Her background is molecular genetics, developmental biology, and toxicology as well as translational informatics, with a focus over the past decade on open science and semantic engineering. Dr. Haendel's vision is to weave together healthcare systems, basic science research, and patient generated data through development of data integration technologies and innovative data capture strategies. Dr. Haendel's research has focused on integration of genotype-phenotype data to improve rare disease diagnosis and mechanism discovery. Examples of her work include:

- National COVID Cohort Collaborative (N3C), a transparent and reproducible national database of harmonized EHR data across Common Data Models (CDMs) for over 6M patients. Monarch Initiative: Community development of ontologies and standards for encoding genotype-phenotype data across species and disease areas. Includes development of the Human Phenotype Ontology and the Mondo disease ontology, a community developed unified disease knowledge across sources and countries. Semantic integration of many ontologies allows population of a large knowledge graph from many sources.
- Center for Cancer Data Harmonization: a semantic engineering program that aims to reconcile data models and terminologies across different Cancer Research Data Commons resources and data modalities to support cross-node query, data harmonization, and multi-modal analytics. Includes use of LinkML for data model harmonization.
- The Global Alliance for Genomics and Health: I lead the Clinical and Phenotypic Capture and Exchange work stream, which has developed Phenopackets, a case-level schema standard for exchanging phenotypic information across journals, registries, EHRs, clinical labs, and patients.



**Susan Redline, MD, MPH**

*Peter C. Farrell Professor of Sleep Medicine at Harvard Medical School, Professor of Epidemiology at Harvard TH Chan School of Public Health, and Director of the Programs in Sleep and Cardiovascular Medicine and Sleep Medicine Epidemiology at Brigham and Women's Hospital.*

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Dr. Redline's research includes epidemiological studies and clinical trials designed to 1) elucidate the etiologies of sleep disorders, including the role of genetic and early life developmental factors; and 2) understand the cardiovascular and other health outcomes of sleep disorders and the role of sleep interventions in improving health. She leads the Sleep Reading Center for a number of major NIH multicenter studies; has led large cohort studies; and leads several large randomized controlled trials. She founded and co-directs the National Sleep Research Resource([www.sleepdata.org](http://www.sleepdata.org)), an international sleep data sharing repository that has focused on making research data easily searchable and accessible, including complex physiological signals captured by overnight sleep studies. The repository also supports community engagement and provides access to a suite of open source signal processing, visualization and data exploration tools.



**Klaus Romero, MD MS FCP**

*Chief Science Officer*

*Executive Director, Clinical Pharmacology*

Critical Path Institute

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Dr. Romero is a clinical pharmacologist and epidemiologist by training, with 17 years combined experience in clinical research. Dr. Romero has been with C-Path since December of 2007, and during his tenure, he established C-Path's Quantitative Medicine Program, which has led data-driven solutions based on clinical pharmacology, pharmacoepidemiology and modeling and simulation for Alzheimer's disease, polycystic kidney disease, tuberculosis, type 1 diabetes, Parkinson's disease, Duchenne muscular dystrophy, kidney transplantation and Huntington's disease, achieving major milestones such as the first regulatory endorsement by FDA and EMA of a clinical trial simulation tool for mild and moderate Alzheimer's Disease and the qualification of an imaging prognostic biomarker for PKD. He is a fellow of the American College of Clinical Pharmacology and the American Society for Clinical Pharmacology and Therapeutics, as well as a founding member of the International Society of Pharmacometrics.





**Alastair Thomson**

*Chief Information Officer*, National Heart, Lung, and Blood Institute, National Institutes of Health  
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Mr. Thomson currently serves as the Chief Information Officer for the National Heart, Lung and Blood Institute at the National Institutes of Health. He leads an IT operation that supports the NHLBI's administrative needs and the Institute's research mission. This includes multi-petabyte scale storage and high-performance computational resources for the 68 labs within the Division of Intramural Research and has built a substantial software development capability. He also supports NHLBI data science initiatives for the heart, lung, blood and sleep (HLBS) research community, including the Trans-Omics for Precision Medicine (TOPMed) program and Cure Sickle Cell initiative. He co-leads the NHLBI's BioData Catalyst eco-system which provides secure cloud based analytic resources to HLBS researchers and democratizes access to HLBS data by making it FAIR (Findable, Accessible, Interoperable and Reusable). He provides leadership for several trans-NIH initiatives such as the Post-Acute Sequelae of SARS-CoV-2/COVID (PASC) RECOVER program. Prior to joining the NHLBI had an eclectic career in industries including government, healthcare, telecommunications, insurance, logistics, broadcast television and computer animation. He established and led the Computer Science Applied Research Center at New Zealand's University of Otago and holds degrees in Psychology and Computer Science. He has particular interests in the application of privacy preserving record linkage (PPRL) to enhance the value of NHLBI datasets, expanding diversity within the HLBS research community and the application of artificial intelligence and machine learning approaches to discovery science.



**Jeffrey Grethe, Ph.D.**

*Associate Director, Neurosciences, University of California San Diego*

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Dr. Jeffrey Grethe has more than 2 decades of experience in providing collaborative data environments to biomedical researchers in order to advance scientific inquiry leading to new discoveries and treatments of human disorders. Within the Center for Research in Biological Systems (CRBS; <http://crbs.ucsd.edu>) at the University of California, San Diego he is the Principal Investigator for the NIDDK Information Network (dkNET; <http://dknet.org>), which serves the needs of basic and clinical investigators by providing seamless access to large pools of data, information, and resources relevant to the mission of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). dkNET builds on an infrastructure foundation provided by the Neuroscience Information Framework (NIF; <http://neuinfo.org>), where Dr. Grethe, as Principal Investigator, led the development of the technical infrastructure. NIF, which provides the largest searchable collection of biomedical resources on the web, is an open source information framework enabling neuroscientists around the world to access a rich virtual environment identifying and providing access to neuroscience-relevant data and resources. Unlike more general search engines, NIF provides deeper access to a more focused set of resources that are relevant to neuroscience, provides search strategies tailored to neuroscience, and also provides access to content that is traditionally “hidden” from web search engines. The infrastructure underlying NIF and dkNET, SciCrunch (<http://scicrunch.org>), now supports a number of research communities. SciCrunch was designed to allow communities of researchers to create focused portals that provide access to resources, databases, information and tools of relevance to their research areas.



**Maryann Martone, Ph.D.**

Professor Emerita, University of California San Diego

*Chair, Governing Board, University of California San Diego*

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Maryann Martone received her BA from Wellesley College in Biological Psychology and Ancient Greek and her Ph. D. in Neuroscience from the University of California, San Diego. She is a professor Emerita at UCSD, but still maintains an active laboratory, the FAIR Data Informatics Lab. She started her career as a neuroanatomist, specializing in light and electron microscopy, but her main research for the past 20 years focused on informatics for neuroscience, i.e., neuroinformatics. She led the Neuroscience Information Framework (NIF), a national project to establish a uniform resource description framework for neuroscience, and the NIDDK Information Network (dknet), a portal for connecting researchers in digestive, kidney and metabolic disease to data, tools, and materials. Dr. Martone is past President of FORCE11, an organization dedicated to advancing scholarly communication and e-scholarship and served as Editor-in-Chief for Brain and Behavior for five years. She completed two years as the chair of the Council on Training, Science and Infrastructure for the International Neuroinformatics Coordinating Facility and is now the chair of the Governing Board. Since retiring, she served as the Director of Biological Sciences for Hypothesis, a technology non-profit developing an open annotation layer for the web (2015-2018) and founded SciCrunch, a technology start up based on technologies developed by NIF and dkNET. Her current projects include dkNET, the Open Data Commons for Spinal Cord Injury and SPARC (Stimulating Peripheral Activity to Relieve Conditions).



**Abel N Kho, MD**

*Director, Institute for Public Health and Medicine (IPHAM) - Center for Health Information Partnerships*

*Director, Institute for Augmented Intelligence in Medicine*

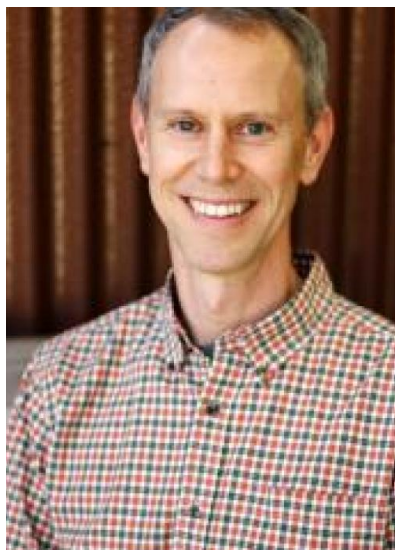
*Professor of Medicine (General Internal Medicine and Geriatrics) and Preventive Medicine (Health and Biomedical Informatics)*

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Dr. Kho is an Internist and Professor of Medicine and Preventive Medicine in the Northwestern University Feinberg School of Medicine where he is the Founding Director of both the Center for Health Information Partnerships (2015) and the Institute for Augmented Intelligence in Medicine (2020). His research focuses on developing regional Electronic Health Record (EHR) enabled data sharing platforms for a range of health applications including high throughput phenotyping, cohort discovery, estimating population level disease burden, and quality improvement.

Dr. Kho leads the Chicago Area Patient Centered Outcomes Research Network (CAPriCORN) one of 11 large scale clinical data research networks (CDRN) built on medical record integration, that are part of the PCORI-funded Patient Centered Outcomes Research Network (PCORnet). In total he has served as Principal Investigator for over \$70M in external funding, published over 100 manuscripts, and mentored numerous students and trainees. He is an internationally recognized expert in privacy preserving record linkage, having published the first large scale real-world application of this method for which he was assigned a patent, and co-founded a startup which was subsequently acquired by Datavant. He is an elected Fellow of the American College of Medical Informatics and recipient of the Donald A.B. Lindbergh Award for Innovation in Informatics.



**Ben Heavner, PhD**

*Senior Research Scientist*

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Dr. Heavner is a Senior Research Scientist in the Biostatistics Department at the University of Washington. He is primary liaison between the NHLBI TOPMed Data Coordinating Center and NHLBI's BioData Catalyst program. Dr. Heavner has experience in designing and implementing cloud-based bioinformatic workflows and participating in collaborative research efforts involving big data, including a leadership role in implementing a workflow for bulk processing ENCODE data for functional genomics under the auspices of the Big Data to Knowledge program, serving as liaison from the TOPMed DCC in the Data Commons Pilot Phase Consortium, and participating in the NIH Workshops on Cloud-Based Platforms Interoperability. Dr. Heavner has written software for parsing annotation produced for TOPMed variants by the WGS pipeline and supported porting his software to BioDataCatalyst in collaboration with Seven Bridges Genomics, incorporated. Dr. Heavner has served as a co-chair of the BioDataCatalyst Data Harmonization Working Group.



**Paul Avillach, M.D., Ph.D.**

Assistant Professor of Biomedical Informatics & Pediatrics, Department of Biomedical Informatics, Harvard Medical School and Children's Hospital Informatics Program, Boston Children's Hospital; Assistant Professor of Epidemiology, Department of Epidemiology, Harvard T.H. Chan School of Public Health

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Paul Avillach holds an MD in public health and epidemiology and a PhD in biomedical informatics. Avillach's research focuses on the development of novel methods and techniques for the integration of multiple heterogeneous clinic cohorts, electronic health records data, and multiple types of genomics data to encompass biological observations. He is PI and Co-PI on several large projects and platforms including the NHLBI BioData Catalyst PIC-SURE, Boston Children's Hospital Biobank, NCATS U01 Genomic Information Commons.



**Jodyn E. Platt, M.P.H., Ph.D.**

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Dr. Platt is an Assistant Professor of Learning Health Sciences trained in medical sociology and health policy. Her research currently focuses on informed consent in cancer and genomic studies, and the Ethical, Legal, and Social Implications (ELSI) of public health genetics, newborn screening, and learning health systems. She is interested in understanding what makes learning health systems trusted and the pathways for earning, achieving, and sustaining trust using qualitative and survey methods.



**Lucila Ohno-Machado, M.D., Ph.D.**

Chair, UCSD Health Department of Biomedical Informatics and Professor of Medicine, University of California San Diego

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Lucila Ohno-Machado, MD, MBA, PhD received her medical degree from the University of São Paulo and her doctoral degree in medical information sciences and computer science from Stanford. She is Associate Dean for Informatics and Technology, and the founding chair of the UCSD Health Department of Biomedical Informatics at UCSD, where she leads a group of faculty with diverse backgrounds in medicine, nursing, informatics, and computer science. Also, she is the PI for the California Precision Medicine Consortium for the NIH All of Us Research Program. Prior to her current position, she was faculty at Brigham and Women's Hospital, Harvard Medical School and affiliated with the MIT Division of Health Sciences and Technology.

Dr. Ohno-Machado is an elected member of the American College of Medical Informatics, the American Institute for Medical and Biological Engineering, the American Society for Clinical Investigation and the National Academy of Medicine. She served as editor-in-chief for the Journal of the American Medical Informatics Association from 2011 to 2018. She directs the patient-centered Scalable National Network for Effectiveness Research, a large clinical data research network covering more than 30 million patients and 12 healthcare systems, and was one of the founders of UC-Research eXchange, a clinical data research network that connected the data warehouses of the five University of California medical centers. She was the director of the NIH-funded National Center for Biomedical Computing iDASH (integrating Data for Analysis, 'anonymization,' and Sharing) based at UCSD with collaborators in multiple institutions, as well as other NIH-funded consortia and research projects.

Her research focuses on privacy-preserving distributed analytics for healthcare and biomedical sciences. She has received numerous awards for innovations in biomedical informatics.