Workshop on Jumpstarting Access to Clinical Data for COVID-19 Research

Moderators, Panelists, Speakers & Researchers

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Opening Remarks

Warren A. Kibbe, PhD

Chief Data Officer, Duke Cancer Institute

Warren A. Kibbe, PhD is Vice Chair and Professor of Biostatistics and Bioinformatics at Duke University, the Informatics leader for the Duke Clinical and Translational Sciences Institute, and the Chief Data Officer for the Duke Cancer Institute. His research interests include data representation for clinical trials, especially improving the computability and interpretability of biomarker and eligibility criteria; data interoperability between medical records and decision support algorithms; improving data representation and interoperability for biomedical research using ontologies, developing novel analysis and visualization tools for next gen sequencing data, especially methylseq. Prior to joining Duke, he served as an acting deputy director of the NCI and was the director of the NCI's Center for Biomedical Informatics and Information for four years. He was one of the architects of the Genomic Data Commons initiative, which was the NCI's foray into creating a highly accessible and highly accessed cancer data repository for clinical, proteomic, imaging and genomic data. Dr. Kibbe has been a proponent for open science and open data in biomedical research and helped define the data sharing policy for the NCI Cancer Moonshot program. He also helped architect the joint NCI-DOE computational and biomedical research collaboration. Dr. Kibbe is the co-Founder of the Cancer Informatics for Cancer Centers (http://Ci4CC.org) society, and through Ci4CC organized twice-yearly meetings of cancer informatics faculty and leaders from the majority of NCI-designated Cancer Centers. Dr. Kibbe is currently a part of the NCATS National COVID Cohort Collaborative (N3C) where he is engaged in the Portals and Dashboards subgroup.

Keynote on COVID-19

Eric Topol, MD

Director & Founder Scripps Research Translational Institute

Eric Topol is the Founder and Director of the Scripps Research Translational Institute, Professor, Molecular Medicine, and Executive Vice-President of Scripps Research. As a researcher, he has published over 1,200 peer-reviewed articles, with more than 270,000 citations, elected to the National Academy of Medicine, and is one of the top 10 most cited researchers in medicine. His principal scientific focus has been on the genomic and digital tools to individualize medicine.

In 2016, Topol was awarded a $207 million grant from the NIH to lead a significant part of the Precision Medicine (All of Us) Initiative, a prospective research program enrolling 1 million participants in the US. This is in addition to his role as principal investigator for a flagship $35M NIH grant to promote innovation in medicine. He has been voted as the #1 most influential physician leader in the United States in a national poll conducted by *Modern Healthcare*. Besides editing several textbooks, he has published 3 bestseller books on the future of medicine: The Creative Destruction of Medicine, The Patient Will See You Now, and Deep Medicine: How Artificial Intelligence Can Make Healthcare Human Again. Topol was commissioned by the UK 2018-2019 to lead planning for the National Health Service's integration of AI and new technologies.

Background

Susan K. Gregurick, PhD

Associate Director of Data Science, National Institutes of Health

Susan K. Gregurick, Ph.D., was appointed Associate Director for Data Science and Director of the Office of Data Science Strategy (ODSS) at the National Institutes of Health on Sept. 16, 2019. Under Dr. Gregurick's leadership, the ODSS leads the implementation of the NIH Strategic Plan for Data Science through scientific, technical, and operational collaboration with the institutes, centers, and offices that comprise NIH. Dr. Gregurick was instrumental in the creation of the ODSS in 2018 and served as a senior advisor to the office until being named to her current position.

Dr. Gregurick was previously the Division Director for Biophysics, Biomedical Technology, and Computational Biosciences at the National Institute of General Medical Sciences. Prior to joining the NIH in 2013, Dr. Gregurick was a program director in the Office of Biological and Environmental Research at the Department of Energy.

Before beginning a career of government service, Dr. Gregurick was a professor of computational chemistry at the University of Maryland, Baltimore County. Her research interests included dynamics of large biological macromolecules, and her areas of expertise are computational biology, high performance computing, neutron scattering and bioinformatics.

Dr. Gregurick received her undergraduate degree in chemistry and mathematics from the University of Michigan and her Ph.D. in physical chemistry from the University of Maryland.

Acquiring and Linking Data from Different Clinical Environments

Lesley H. Curtis, PhD

Co-Investigator - Patient Centered Outcomes Research Initiative Network (PCORnet)

Lesley H. Curtis is Professor and Chair of the Department of Population Health Sciences in the Duke School of Medicine. A health services researcher by training, Dr. Curtis is an expert in the use of health care and Medicare claims data for health services and clinical outcomes research, and a leader in national data quality efforts. Dr. Curtis serves as co-PI of the FDA's Sentinel Innovation Center, Co-Investigator of the Data Core for the FDA's Sentinel Initiative to monitor the safety of FDA-regulated medical products, and Chair of the Data Quality Subcommittee for the National Evaluation System for health Technology (NEST) Coordinating Center that generates real-world evidence for health technology and medical devices. She serves as co-Investigator of the coordinating center for PCORI's National Clinical Research Network (PCORnet), working with health systems and patient networks to develop a harmonized network infrastructure that leverages health systems and electronic health record data for robust observational and interventional research.

George Hripcsak, MD, MS

Vivian Beaumont Allen Professor, Chair of Biomedical Informatics, Columbia, Director of Medical Informatics Services for NewYork-Presbyterian Hospital

George Hripcsak, MD, MS, is Vivian Beaumont Allen Professor and Chair of Columbia University's Department of Biomedical Informatics and Director of Medical Informatics Services for NewYork-Presbyterian Hospital/Columbia Campus. He is a board-certified internist with degrees in chemistry, medicine, and biostatistics. Dr. Hripcsak's research focus is

on the clinical information stored in electronic health records and on the development of next-generation health record systems. Using nonlinear time series analysis, machine learning, knowledge engineering, and natural language processing, he is developing the methods necessary to support clinical research and patient safety. He leads the Observational Health Data Sciences and Informatics (OHDSI) coordinating center; OHDSI is an international network with 200 researchers. Dr. Hripcsak is a member of the National Academy of Medicine, the American College of Medical Informatics, the International Academy of Health Sciences Informatics, and the New York Academy of Medicine. He has published over 350 papers.

Chris Chute, MD, DrPH

Bloomberg Distinguished Professor, Chief Research Information Officer, Johns Hopkins Medicine

Dr. Chute is the Bloomberg Distinguished Professor of Health Informatics, Professor of Medicine, Public Health, and Nursing at Johns Hopkins University, and Chief Research Information Officer for Johns Hopkins Medicine. He received his undergraduate and medical training at Brown University, internal medicine residency at Dartmouth, and doctoral training in Epidemiology and Biostatistics at Harvard. He is Board Certified in Internal Medicine and Clinical Informatics, and an elected Fellow of the American College of Physicians, the American College of Epidemiology, HL7, the American Medical Informatics Association, and the American College of Medical Informatics (ACMI), as well as a Founding Fellow of the International Academy of Health Sciences Informatics; he was president of ACMI through 2018. His career has focused on how we can represent clinical information to support analyses and inferencing, including comparative effectiveness analyses, decision support, best evidence discovery, and translational research. He has had a deep interest in semantic consistency, harmonized information models, and ontology. His current research focuses on translating basic science information to clinical practice, and how we classify dysfunctional phenotypes (disease). He became founding Chair of Biomedical Informatics at Mayo Clinic in 1988, retiring from Mayo in 2014, where he remains an emeritus Professor of Biomedical Informatics. He is presently PI on a spectrum of high-profile informatics grants from NIH spanning translational science. He has been active on many HIT standards efforts and chaired ISO Technical Committee 215 on Health Informatics and the World Health Organization (WHO) International Classification of Disease Revision (ICD-11).

Jessie Tenenbaum, PhD

Chief Data Officer (CDO) for North Carolina's Department of Health and Human Services

Jessica Tenenbaum, PhD, is the Chief Data Officer (CDO) for North Carolina's Department of Health and Human Services. In this role, Dr. Tenenbaum is responsible for the development and oversight of departmental data governance and strategy to enable data-driven policy for improving the health and well-being of North Carolinians. Dr. Tenenbaum is also a faculty member in Duke University's Department of Biostatistics and Bioinformatics. Nationally, Dr. Tenenbaum is a member of the Board of Directors for the American Medical Informatics Association (AMIA) and serves on the Board of Scientific Counselors for the National Library of Medicine.

Dr. Griffin Weber

Associate Professor of Biomedical Informatics, Harvard Medical School

Griffin Weber directs the Biomedical Research Informatics Core (BRIC) at BIDMC. A result of his research in expertise mining and social network analysis is his invention of an open source social networking website for scientists called Profiles RNS, now used at dozens of universities across the country. It automatically mines large datasets such as PubMed, NIH ExPORTER, and the U.S. patent database to discover investigators' research areas and scientific networks. It then presents these connections using temporal, geospatial, and network visualizations. The software has numerous applications, ranging from finding individual collaborators and mentors to understanding the dynamics of an entire research community.

Weber is also an investigator on Informatics for Integrating Biology and the Bedside (i2b2), an NIH National Center for Biomedical Computing, for which he helped developed a web-based open source platform that enables a variety of functions, including queries of large clinical

repositories for hypothesis testing and identification of patients for clinical trials. He also created the original prototype software for the Shared Health Research Information Network (SHRINE), which is a federated query tool that connects i2b2 databases across multiple institutions. More than 100 institutions worldwide use i2b2 and SHRINE to support clinical research.

Weber received his M.D. and Ph.D. in computer science from Harvard University in 2007. While still a student, he became the first Chief Technology Officer of Harvard Medical School and built an educational web portal that provides interactive online content to over 500 courses. His past research projects also include analyzing DNA microarrays, modeling the growth of breast cancer tumors, and creating algorithms for predicting life expectancy.

Creating and Using Platforms

Justin Guinney, PhD

Vice President of Computational Oncology, Sage Bionetworks

Justin Guinney is the Vice President of the Computational Oncology group at Sage Bionetworks. His group contains specialists from multiple domains, including molecular biology, computer science, and oncology, and focuses on the development of computational models for optimizing patient diagnosis, prognosis, and treatment in cancer. Dr. Guinney is an expert at large-scale analysis of genomic data and works regularly with clinicians to link these models to complex cancer phenotypes. Prior to joining Sage Bionetworks, he co-founded and managed a software company called FiveSight Technologies, now part of Intalio Corp. Dr. Guinney received a BA from the University of Pennsylvania in History, a BS from the University of Illinois, Urbana-Champaign in Electrical Engineering, and a PhD from Duke University in Computational Biology and Bioinformatics.

Josh Denny, MD, MS

Chief Executive Officer (CEO), NIH's All of Us Research Program

Josh Denny is the Chief Executive Officer of the National Institutes of Health's *All of Us* Research Program. He has been involved in *All of Us* from its inception, first as a member of the Advisory Committee to the (NIH) Director Precision Medicine Initiative Working Group, which developed the program's initial scientific blueprint. He led the program's initial prototyping project and served as the principal investigator for the *All of Us* Data and Research Center.

As a physician scientist, Josh is deeply committed to improving patient care through the advancement of precision medicine. Before joining the NIH, Josh was a Professor of Biomedical Informatics and Medicine, Director of the Center for Precision Medicine, and Vice President for Personalized Medicine at Vanderbilt University Medical Center. In his roles at VUMC, he was both a practicing internist and a researcher. His research interests include use of electronic health records (EHRs) and genomics to better understand disease and drug response. He also led efforts implementing precision medicine to improve patient outcomes. Josh was a leader in the development of phenome-wide association studies (PheWAS) and phenotype risk scores. He served as PI for Vanderbilt sites in the Electronic Medical Records and Genomics (eMERGE) Network, Pharmacogenomics Research Network (PGRN), and the Implementing Genomics into Practice (IGNITE) Network.

Melissa Haendel, PhD

Director of the NCATS Center for Data to Health at Oregon Health & Science University, co-leads the National COVID Cohort Collaborative (N3C)

Melissa Haendel is the Director of the NCATS Center for Data to Health at Oregon Health & Science University, and in this role also co-leads the National COVID Cohort Collaborative (N3C). The N3C aims to aggregate and harmonize COVID-19 relevant EHR data from across the US and support collaborative analytics, machine learning, and large-scale statistical analysis to reveal key factors and drug candidates. Dr. Haendel co-founded the Monarch Initiative, an international consortium that provides open, semantically integrated access to human and model organism genotype-phenotype data, and the Human Phenotype Ontology used extensively in rare disease diagnostics. Dr. Haendel is passionate about open, collaborative, reproducible science. She co-leads the Clinical and Phenotypic workstream in the Global Alliance for Genomics and Health (GA4GH), which helps realize standards and policies for genomic health data sharing, including the newly released Phenopackets exchange standard. Dr. Haendel's recent work focuses on modeling environmental exposures and their interactions with an individual's genomic endowment, and clinical data model harmonization and terminology services to support translational interoperability.

Alastair Thomson

Chief Information Officer, National Heart, Lung and Blood Institute, National Institute of Health

Mr. Thomson serves as the Chief Information Officer for the NHLBI. He oversees the IT infrastructure that supports 68 laboratories in the NHLBI Intramural Research Program and provides IT support to 1800 NHLBI staff. He is member of the NHLBI's Data Science Leadership Team, co-leads the NHLBI BioData Catalyst program and works with critical NHLBI and trans-NIH programs such as the Cure Sickle Cell Initiative, the Regenerative Medicine Innovation Catalyst and several COVID-19 related programs. He is a graduate of the University of Otago, Dunedin, New Zealand and holds degrees in psychology and computer science and has had a diverse career including as Director of the University of Otago's Computer Science Applied Research Center, co-founding Animation Research Limited, one of Southern Hemisphere's leading provider of 3D computer graphics and animation and served as a consultant to industries including finance, logistics, insurance. He has been with the NIH for 19 years and has worked for OD, NCI, NIGMS, CIT and NHLBI.

Generalizability, Reproducibility, & Validity

Robert M. Califf, MD, MACC

Former Commissioner of Food and Drugs Administration 2016-2017

Robert M. Califf, MD, MACC, is the Head of Clinical Policy and Strategy for Verily and Google Health for Verily and Google Health. Prior to this Dr. Califf was the vice chancellor for health data science for the Duke University School of Medicine; director of Duke Forge, Duke's center for health data science; and the Donald F. Fortin, MD, Professor of Cardiology. He served as Deputy Commissioner for Medical Products and Tobacco in the U.S. Food and Drug Administration (FDA) from 2015-2016, and as Commissioner of Food and Drugs from 2016-2017. A nationally and internationally recognized leader in cardiovascular medicine, health outcomes research, healthcare quality, and clinical research, Dr. Califf is a graduate of Duke University School of Medicine. Dr. Califf was the founding director of the Duke Clinical Research Institute and is one of the most frequently cited authors in biomedical science.

Amy Abernethy, MD, PhD

Principal Deputy Commissioner, Food and Drug Administration

Amy P. Abernethy, M.D., Ph.D. is an oncologist and internationally recognized clinical data expert and clinical researcher. As the Principal Deputy Commissioner of Food and Drugs, Dr. Abernethy helps oversee FDA's day-to-day functioning and directs special and high-priority cross-cutting initiatives that impact the regulation of drugs, medical devices, tobacco and food. As acting Chief Information Officer, she oversees FDA's data and technical vision, and its execution. She has held multiple executive roles at Flatiron Health and was professor of medicine at Duke University School of Medicine, where she ran the Center for Learning Health Care and the Duke Cancer

Care Research Program. Dr. Abernethy received her M.D. at Duke University, where she did her internal medicine residency, served as chief resident, and completed her hematology/oncology fellowship. She received her Ph.D. from Flinders University, her B.A. from the University of Pennsylvania and is boarded in palliative medicine.

Philip R.O. Payne, PhD, FACMI, FAMIA

Associate Dean, Chief Data Scientist at the Washington University School of Medicine

Dr. Payne is the Associate Dean for Health Information and Data Science and Chief Data Scientist at the Washington University School of Medicine. In addition, he is the Janet and Bernard Becker Professor and founding Director of the school's Institute for Informatics (I2). Dr. Payne is the author of over 200 publications focusing on the intersection of biomedical informatics, data science, and the clinical and translational science domains, including several seminal reports that have served to define the field of Clinical Research Informatics. The work underway in his laboratory currently focuses on: 1) machine learning and cognitive computing approaches to the discovery and analysis of bio-molecular and clinical phenotypes; 2) interventional approaches to the use of electronic health records and clinical decision support systems; and 3) the design and evaluation of open-science platforms that enable collaborative and cumulative approaches to scientific discovery.

Judy Murphy, RN, FACMI, FHIMSS, FAAN

Chief Nursing Officer, IBM Global Healthcare

Judy Murphy, RN, FACMI, FHIMSS, FAAN is Chief Nursing Officer for IBM Global Healthcare, where she is strategic advisor to clients. Prior to IBM, she was Deputy National Coordinator for Programs and Policy at the ONC in Washington DC where she led federal efforts to assist in the adoption of health IT. She came to ONC with 25 years of experience as VP-EHR Applications at Aurora Health Care in Wisconsin, where she led their EHR program since 1995. She publishes and lectures nationally and internationally. She is a Fellow in the American Academy of Nursing, the American College of Medical Informatics and HIMSS. She has received numerous awards, including the HIMSS 2018 Most Influential Women in Health IT and the AMIA 2014 Award for Health Policy Contributions in Informatics.

Things to Consider: Governance, IRB, DACs, Eligibility, and Security & Confidentiality

Stan Ahalt, PhD

Chief Information Technology Resources Branch (ITRB), NCATS

Stan Ahalt, Ph.D., 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-CH, Duke, and NC State as well as with partners across the country. RENCI's role is to provide enabling cyberinfrastructure to these research collaborations, which entails working on the challenges of data management, sharing, integration, and security. Ahalt is also a professor in the UNC-CH

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. Ahalt earned his doctorate in Electrical and Computer Engineering from Clemson University and has over 30 years of experience in high performance computing, signal processing, and pattern recognition

Sam Michael

Chief, Information Technology Resources Branch (ITRB), NCATS

I have been the chief of the Information Technology Resources Branch (ITRB) at NCATS for over 5 years now after having spent the previous 10 years as the lead of the Automation and Compound Management group (ACOMM). While working as the lead of ACOMM, the group successfully completed hundreds of high throughput screens (HTS) spanning a multitude of complex assay types that have led to hundreds of probe compounds and several investigational new drugs (IND). These hundreds of HTS campaigns required over 1 million 1536 well assay plates to execute, representing billions of data points generated. We also helped establish critical platforms such as combination screening, automated tissue culture, and the 3D tissue group which are currently in use at NCATS to help advance our scientific mission. The sheer volume of production and complex systems required to generate and analyze this volume of scientific data led me to realize that laboratory automation was essentially a complex information technology (IT) problem, so when the opportunity arose to become the acting chief information officer (CIO) at NCATS I took it. To ensure that there was no disconnect between the scientific needs of the center and the IT resources required to meet them, the ITRB group was formed to essentially merge the two. The group now has three distinct components, the Research Services Core (RSC), which is responsible for all intramural scientific platforms at NCATS, the Information Technology Services Section (ITSS) , which is responsible for all IT systems across the center; both intramural and extramural, and the Cybersecurity Section (CSS), which is responsible for ensuring the security and privacy of all NCATS systems. ITRB is responsible for the development, operation, maintenance, security, and continuous improvement of multiple automated systems, including several complex cloud environments supporting thousands of users across both NIH and the extramural community. Our responsibility is to build and support these secure scientific collaborative platforms to enable the scientific mission of NCATS.

Craig Hayn

Chief Information Systems Security Officer (CISSO), National Cancer Institute

Mr. Hayn has worked at the National Cancer Institute (NCI) for the past 13 years, 12 of which were as a contractor with Booz Allen Hamilton (Booz Allen) before taking the federal position of CISSO in 2019. His background in cybersecurity dates to 1989 when he began working at the Department of Energy's since-decommissioned Rocky Flats Nuclear Weapons Plant in Golden, Colorado. Craig grew up in Colorado but after four years at Rocky Flats he moved east to Maryland in 1993 where he later finished his undergraduate studies at the University of Maryland University College. From 1993-2001 Craig worked for SAIC as the IT and Network Systems Administrator for their contract with the U.S. Army's Medical Research and Materiel Command. In 2001 he joined Booz Allen where he successfully led numerous cybersecurity programs and projects for multiple large federal agencies including the Food and Drug Administration, The Department of Housing and Urban Development, The Social Security Administration, The Department of Education, and The National Institutes of Health (NIH). It was at Rocky Flats, though, where Craig first discovered his love for cyber security, building and securing local area networks for the Nuclear Safety Engineering Department. This passion and love for cyber security has only deepened since then. Today, as the NCI's CISSO he oversees securing NCI's vast IT infrastructure of over 14,000 endpoints, its networks, cloud infrastructure, and the data and information that are critical to NCI's research mission. While these duties are in themselves highly rewarding, the most rewarding of part of his job is having the opportunity to work with such incredibly talented, driven and diverse people from all over the globe who all share the same drive and passion to hopefully, someday, find a cure for cancer.

John Wilbanks

Chief Commons Officer, Sage Bionetworks

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 co-led 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.

Mike Tartakovsky

Chief Information Officer and Director of the Officer of Cyber Infrastructure and Computational Biology (OCICB), NIAID

Mr. Michael Tartakovsky is the Chief Information Officer and Director of the Office of Cyber Infrastructure and Computational Biology (OCICB) for the National Institute of Allergy and Infectious Diseases (NIAID), National Institutes of Health (NIH). In these roles he provides strategic leadership and technical direction for information and information technologies initiatives to support and enable NIAID biomedical research mission. Since 2003, Mr. Tartakovsky has led his office in delivering to NIAID state-of-the-art Scientific Computing Infrastructure, Custom Software Applications, Bioinformatics tools, and Data Analytics. Many solutions developed under Mr. Tartakovsky leadership are now used by NIH and also available as a service to the broader scientific community. In 2004 Mr. Tartakovsky established the NIAID OCICB Bioinformatics and Computational Bioscience Branch, articulating strategic collaborative goals and communications initiatives that emphasize the cutting-edge role of bioinformatics and computational sciences and technologies. He is a member of the US

Government Senior Executive Service (SES) and a recipient of the 2015 President's Meritorious Executive Award.

Jaime M. Guidry Auvil, PhD

Director of the Office of Data Sharing (ODS), National Cancer Institute (NCI)

Dr. Jaime M. Guidry Auvil serves as the Director of the Office of Data Sharing (ODS) at the National Cancer Institute (NCI). In her role, Dr. Guidry Auvil leads NCI's approach to development and implementation of data sharing and public access policies to enhance NCI's mission. She advises NCI programs and leadership on cancer data policy matters of significance to the Institute, the research community, and the public, on a wide range of issues including data organization, management, access and sharing of NCI-supported research. Since joining NCI in 2010, Dr. Guidry Auvil has led high-priority data sharing initiatives within NCI's Office of the Director, most extensively for large-scale pediatric cancer initiatives including Therapeutically Applicable Research to Generate Effective Treatments (TARGET) initiative and the Childhood Cancer Data Initiative (CCDI). She additionally serves as an NCI representative on leadership and working group teams to provide guidance for the Gabriella Miller Kids First Pediatric Research Program through the NIH Office of the Director.

Prior to joining NIH, Dr. Guidry Auvil led clinical and biomedical translational research studies within academia (Veteran Affairs Hospital of Baltimore, and University of Maryland Medical School) and the biotechnology industry (BBI Biotech, Inc.). Dr. Guidry Auvil received her doctorate in tumor biology and biomedical sciences from Georgetown University Medical School, where her research on adhesion molecule, cadherin-11, in metastatic cancers led to the development of a patented small molecule inhibitor intended for the treatment of both bone metastatic cancers and rheumatoid arthritis. Dr. Guidry Auvil received her undergraduate degree in health sciences from Wake Forest University.

Considering Issues of Diversity and Representativeness

Oluwadamilola "Lola" Fayanju, MD, MA, MPHS, FACS

Assistant Professor of Surgery, Population Health Sciences, Duke University School of Medicine, Associate Director for Disparities & Value in Healthcare with Duke Forge, and Director of the Durham VA Breast Clinic

Dr. Fayanju is an Assistant Professor of Surgery and Population Health Sciences in the Duke University School of Medicine, Associate Director for Disparities & Value in Healthcare with Duke Forge, and Director of the Durham VA Breast Clinic. Her research focuses on health disparities, aggressive breast cancer variants, and improving value in oncology, particularly through the collection and application of patient-reported outcomes (PROs). In 2019, she was recognized by the National Academy of Medicine (NAM) as an Emerging Leader in Health and Medicine Scholar, selected as one of 10 early- and mid-career researchers nationwide felt to "represent the next generation of leading scientists, health care providers, public health professionals, and policymakers." Her research, which is currently supported by a K08 career development award from the National Institutes of Health (NIH), has been recognized with the receipt of two Conquer Cancer Merit Awards from the American Society of Clinical Oncology (ASCO), and she has been published in a variety of journals including *Annals of Surgery, Cancer,* and *JAMA*.

Finalize, Vision and Next Steps

Robert L. Grossman, PhD

Principal Investigator for the NCI GDC, University of Chicago

Robert L. Grossman, PhD, is the Frederick H. Rawson Distinguished Service Professor in Medicine and Computer Science and the Jim and Karen Frank Director of the Center for Translational Data Science at the University of Chicago. He has served as the chief research informatics officer of the Biological Sciences Division at the University of Chicago since 2011. He is also the Co-Chief in the Section of Computational Biomedicine and Biomedical Data Science in the Department of Medicine. He serves as chair of the Open Commons Consortium, a nonprofit that develops and operates data commons to support research in science, medicine, health care, and the environment.

Patricia Flatley Brennan, RN, PhD

Director, National Library of Medicine

Dr. Brennan is the Director of the National Library of Medicine (NLM) at the National Institutes of Health (NIH), where she oversees the world's largest biomedical library. Since becoming director in August 2016, she has positioned the Library to be the hub for biomedical data science at NIH and across the biomedical research enterprise globally. She spearheaded the development of a new strategic plan that refocuses and enhances NLM's research, development, training and information systems. By leveraging NLM's heavily used data and information resources and programs, Dr. Brennan is strengthening and advancing NLM's data infrastructure to accelerate data-driven discovery and health, engage new users in new ways, and develop the workforce for a data-driven future.

Dr. Brennan is a pioneer in the development of innovative information systems and services, and her professional accomplishments reflect her background, which unites engineering, information technology, and clinical care to improve the public health and ensure the best possible experience in patient care. Dr Brennan holds an appointment as associate investigator in the National Institute of Nursing Research Division of Intramural Research, where she directs the Advanced Visualization Laboratory.

Prior to joining NIH, she was the Lillian L. Moehlman Bascom Professor in the School of Nursing and College of Engineering at the University of Wisconsin–Madison and also led the Living Environments Laboratory (now the Virtual Environments Group) at the Wisconsin Institute for Discovery.

A past president of the American Medical Informatics Association, Dr. Brennan was elected to the National Academy of Medicine in 2001. She is a fellow of the American Academy of Nursing, the American College of Medical Informatics, and the New York Academy of Medicine.

In 2020, Dr. Brennan was inducted into the American Institute for Medical and Biological Engineering (AIMBE). The AIMBE College of Fellows is among the highest professional distinctions accorded to a medical and biological engineer.

Use Cases

Dr. Matthew A. Cavender, MD, MPH

Assistant Professor at the University of North Carolina in Chapel Hill, NC

Dr. Matthew A. Cavender, MD, MPH is an Assistant Professor at the University of North Carolina in Chapel Hill, NC. He received his medical degree from the University of Alabama School of Medicine and a Master's of Public Health from the Harvard School of Public Health. He completed an internship and residency in Internal Medicine at Duke University in Durham, North Carolina, clinical fellowship in cardiology at the Cleveland Clinic in Cleveland, Ohio, and a research and interventional cardiology fellowship at Brigham and Women's Hospital in Boston, Massachusetts.

He is clinically active as an interventional cardiologist and specializes in transcatheter therapies for patients with advanced coronary artery disease, peripheral vascular disease and valvular heart disease. He has extensive experience in clinical research studying the clinical effectiveness of clinical interventions, devices, and pharmacotherapies. His research efforts are focused on the effectiveness of existing treatment strategies and therapies for patients with cardiovascular disease, the impact of diabetes on cardiovascular events among patients with coronary artery disease, and pharmacologic and interventional strategies to improve outcomes in patients with diabetes and atherosclerosis.

Dr. Cavender is a Fellow of the American College of Cardiology and member of a number of medical societies and organizations, including the American Heart Association Council of Clinical Cardiology, and the Society for Cardiovascular Angiography and Interventions. Dr. Cavender has authored numerous works on pharmacologic and interventional therapies for patients with coronary artery disease, valvular heart disease, diabetes, and myocardial infarction that have been published in peer-reviewed journals including The New England Journal of Medicine, The Lancet, Circulation and The Journal of the American College of Cardiology. He currently is an

Assistant Editor for Circulation: Cardiovascular Interventions and is the Co-Director of Cardiovascular Clinical Trials at the University of North Carolina.

Elaine Hill, PHD

Applied Microeconomist

As an applied microeconomist, Dr. Hill's primary research interests are in health economics and environmental economics. In particular, her research focuses on the intersection between health, health policy, the environment and human capital formation. The unifying theme within these broad areas is the use of quasi-experimental designs and data science to identify modifiable factors that are policy relevant. Dr. Hill is a recipient of the NIH Director's Early Independence Award. She is also affiliated with Wilmot Cancer Institute, the Goergen Institute for Data Science, the Environmental Health Sciences Center, and maintains courtesy faculty positions at external institutions. Dr. Hill received her BA in Economics and Mathematics at Oberlin College in 2005 and her PhD in Applied Economics from Cornell University in 2014.

Adam Resnick, PhD

Research scientist in the Department of Biomedical and Health Informatics, Director for Neurosurgical Translational Research, Alexander B. Wheeler Endowed Chair in Neurosurgical Research at Children's Hospital of Philadelphia (CHOP), and Co-Director of the Center for Data Driven Discovery in Biomedicine (D^3b) at CHOP

Adam Resnick, PhD, is a research scientist in the Department of Biomedical and Health Informatics, Director for Neurosurgical Translational Research, and Alexander B. Wheeler Endowed Chair in Neurosurgical Research at Children's Hospital of Philadelphia (CHOP). Dr. Resnick is also Co-Director of the Center for Data Driven Discovery in Biomedicine (D^3b) at CHOP, leading a multidisciplinary team to build and support a scalable, patient-focused healthcare and educational discovery ecosystem on behalf of all children.

Dr. Resnick's research focuses on defining the cell signaling mechanisms of oncogenesis and tumor progression in brain tumors, to elucidate the molecular and genetic underpinnings of each tumor in an effort to identify and develop targeted therapies.

Dr. Resnick serves as Scientific Chair for the Children's Brain Tumor Tissue Consortium and Pacific Pediatric Neuro-Oncology Consortium, which include over 20 pediatric hospitals worldwide. He is also Principal Investigator for the Gabriella Miller Kids First Data Resource Center.

Charisse Madlock-Brow, PhD

Faculty member in Health Informatics and Information Management at the University of Tennessee Health Science Center

Charisse Madlock-Brown is a faculty member in Health Informatics and Information Management at the University of Tennessee Health Science Center. She received her Master's in Library Science and Ph.D. in Health Informatics from the University of Iowa. She has expertise in data management, data mining, and visualization. She has a broad background in health informatics, with a current focus on obesity trends and multimorbidity. Other areas of interest are network analysis and emerging topic detection in biomedicine. She has authored several book chapters and journal articles and continues to keep up-to-date on data integration, data architecture, database management, and analytic methods. She runs the UTHSC *Research Pipelines* labs, which provide online interfaces for distributed computing and storage systems. Her lab can manage projects from data extraction and transformation to modeling and visualization for small-scale and big data projects.

Paul Harris, PHD, FACMI, FIAHSI

Director of the Vanderbilt University Medical Center Office of Research Informatics

Dr. Harris is professor of biomedical informatics and biomedical engineering with extensive experience working in the field of clinical and translational research informatics. He serves as director of the Vanderbilt University Medical Center Office of Research Informatics and is very active in the NIH Clinical and Translational Science Award (CTSA) informatics community. In addition to supporting the Vanderbilt University research enterprise, Dr. Harris devised and created REDCap (www.projectredcap.org), a data collection platform that has seen widespread adoption by more than 4300 institutional partners and over 1.3 million end-users across 138 countries. He also created and runs a national program (www.researchmatch.org) designed to match individuals wishing to volunteer for studies and researchers recruiting patients for studies and trials. ResearchMatch is serving approximately 150,000 research volunteers and 176 research institutions. Dr. Harris serves as contact PI for the *All of Us* Data and Research Center (DRC) program and the NCATS Recruitment Innovation Center (RIC).

Wilbert Van Panhuis, MD PhD

Assistant Professor of Epidemiology and Biomedical Informatics; Affiliated Faculty, Public Health Dynamics Lab; Director, MIDAS Coordination Center

I am an infectious disease epidemiologist with training in Medicine (Amsterdam) and Global Disease Epidemiology (Johns Hopkins). I am Assistant Professor in the Departments of Epidemiology and Biomedical Informatics. My research in the fields of computational epidemiology and population health informatics aims to improve the efficient use of information for public health action. I aim to improve the discovery and integration of data for population health research, both by humans and machines. I also use large-scale public health data to study the spatial-temporal spread of infectious diseases. I lead multiple large-scale population health informatics projects, including Project Tycho, an open-access repository for global disease surveillance data (NEJM, New York Times, Wall Street Journal). I also direct the Coordination Center of the Models of Infectious Disease Agents Study (MIDAS) funded by the National Institute of General Medical Sciences. MIDAS is a global network for infectious disease modeling central to the current COVID-19 modeling response. We work with researchers around the world and with health agencies, including the US Centers for Disease Control and the World Health Organization. My disease expertise concentrates on vaccine-preventable diseases and vector borne diseases in countries around the world (NEJM, PNAS, NIH Director's Blog).