

GetPreCiSe Annual Meeting

September 7, 2023

8 am – 5 pm

Board of Trust Room
Student Life Center
Vanderbilt University
310 25th Ave S
Nashville, TN 37212

Save
the
Date

Agenda
available
September 1st

Guest Speakers:

Dr. Deven McGraw



Deven McGraw is the lead for Data Stewardship and Data Sharing at Invitae, a clinical genetic medicine company. Previously, she co-founded and served as Chief Regulatory Officer for Ciitizen, a platform for patients to gather and manage their health information, prior to its acquisition by Invitae in 2021. From 2015-2017, she directed U.S. health privacy and security as Deputy Director, Health Information Privacy at the HHS Office for Civil Rights and Chief Privacy Officer (Acting) of the Office of the National Coordinator for Health IT. She was recently appointed by GAO to a three-year term on the Health Information Technology Advisory

Committee. Widely recognized for her expertise in health privacy, she directed the Health Privacy Project at the Center for Democracy & Technology for six years, testifying before Congress on health privacy issues on multiple occasions and leading the privacy and security policy work for the HITECH Health IT Policy Committee. She also is currently serving on the Data and Surveillance Workgroup of the CDC's Advisory Committee to the Director on CDC's Data Modernization. She previously was the Chief Operating Officer of the National Partnership for Women and Families and, before joining federal government service, advised health industry clients on HIPAA compliance and data governance while a partner at Manatt, Phelps & Phillips, LLP. Deven graduated magna cum laude from Georgetown University Law Center and has a Master of Public Health from Johns Hopkins University.

Privacy Protections to Power a Learning Health System

Health and health-relevant data are key to driving medical discovery and achieving a "learning health system." Yet data collected for health purposes are sensitive, and privacy laws do not necessarily protect all health-relevant data against a broad

range of individual and community risks. But efforts to address privacy gaps tend to over-focus on issues of consent and de-identification, failing to address major areas of mistrust of health data use. Such efforts also tend to over-focus on protecting the data, ignoring the need to make data more widely available to inform public health and research initiatives. This talk addresses why it is essential to address gaps in health privacy protections, while also encouraging appropriate and responsible data uses, and what types of policy approaches may be more effective in striking this balance.

Dr. Gail Henderson



Gail E. Henderson, PhD, is professor of Social Medicine in the School of Medicine and adjunct professor of Sociology at the University of North Carolina at Chapel Hill. A medical sociologist with training in public health, she has extensive experience with interdisciplinary research and teaching. She was Department Chair from 2009 to 2015, Director of the UNC Center for Genomics and Society (CGS) from 2007-2019, and co-Director of the Center for AIDS Research (CFAR) International Core from 2004-2014. Since 2019 the GCS has been supported with funds from the UNC School of Medicine. Henderson was the Ethical, Legal and Social Implications (ELSI) Editor of the journal, *Genetics in Medicine*, from 2009-2017, and has been a Member of the National Human Genome Research Institute (NHGRI) Advisory Council from 2016-2019. Her research focuses on these areas: 1) ethical dilemmas and decision making in early phase clinical trials; 2) oversight of biobanks and specimen sharing; 3) preventive genomic screening; 4) race/ethnicity and genomics; and 5) global health, HIV/AIDS, and research ethics. With Dr. Giselle Corbie-Smith, she explored perceptions of genetic variation research among black and white participants, and the role of race and trust in tissue/blood donation for genetic research. Collaborating with UNC researchers on studies of clinical sequencing for UNC patients, she and colleagues documented attrition of minority participants in these clinical trials. She is committed to integrating themes of equity into her teaching in the School of Medicine. In addition, she recently joined UNC colleagues in genetics and informatics to develop an interdisciplinary program for minority students at North Carolina HBCUs and community colleges, to encourage them to enter genomics fields. And most important, she is a wonderfully generous, thoughtful, and inspiring collaborator and mentor.

CEERs: Looking back, looking forward

Dr. Henderson will discuss lessons learned from the UNC CEER (CGS-Center for Genomics and Society) during its 15 years of support from 2004-2019. To engage nearly 20 faculty at UNC, funding was to everyone with small FTE amounts, with larger amounts reserved for center leaders. The programmatic approach shifted from funding a diverse range of unrelated ELSI activities, often attached to larger grants, to focusing on one multidisciplinary cutting-edge project (on population genomic screening). CGS thus reflected changes in ELSI programmatic concerns, but was this shift to one large project a successful strategy? How is this related to successful “sunsetting” of our center at UNC? Dr. Henderson will address broader issues in the ELSI field, including whether CEERs have accomplished the goals for which they were first established, and how transferable the ELSI model is to non-genomics fields.