



HHS Presents “Data Min(d)ing: Privacy and Our Digital Identities”

Hubert H. Humphrey Building
200 Independence Ave, SW
Washington, DC 20201

Monday, October 22, 2018
9:15 a.m.-4:15 p.m.

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| 8:45-9:15 a.m. | Registration |
| 9:15-9:20 a.m. | Opening Remarks |
| 9:20-9:30 a.m. | Welcome to Symposium Attendees |
| 9:30-10:30 a.m. | Panel 1: Genetic Privacy and Data Sharing |

Katherine D. Blizinsky, PhD; Policy Director, *All of Us* Research Program, National Institutes of Health; Assistant Professor, Rush Alzheimer’s Disease Center, Rush University.

Presentation: “Responsiveness and Responsibility: Multidirectional Genomic Data Sharing in the Age of Precision Medicine”

James W. Hazel, PhD, JD; Research Fellow, Center for Biomedical Ethics and Society, Vanderbilt University Medical Center.

Presentation: “Who Knows What, and When?: A Survey of the Privacy Policies Proffered by U.S. Direct-to-Consumer Genetic Testing Companies”

Anthony W. Orlando, PhD; Assistant Professor, Finance, Real Estate, & Law, California State Polytechnic University, Pomona.

Arnold J. Rosoff, JD; Professor Emeritus of Legal Studies and Health Care Management, The Wharton School, University of Pennsylvania.

Presentation: “Genetic Exceptionalism and Special Threats to Privacy: Why Are These Data Different?”

Carson Martinez, MBioethics; Policy Fellow, Future of Privacy Forum.

Presentation: “A Practical Path Towards Genomic Privacy in the United States”

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| 10:30-10:45 a.m. | Break |
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10:45-11:45 a.m. **Panel 2: Regulatory Approaches and Health Data**

Lara Cartwright-Smith, JD, MPH; Associate Professor and Program Director, MPH in Health Policy Program, Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University.

Presentation: “Health Information Ownership: Legal Theories and Policy Implications”

Jason Chung, JD, MSc; Senior Research Scholar, Sports and Society, NYU School of Professional Studies.

Presentation: “The Pressing Need for a National Health Data Strategy”

Fazal Khan, MD, JD; Associate Professor, University of Georgia School of Law.

Presentation: “Regulating Carebots for the Elderly: Is Safety and Efficacy Enough?”

Efthimios Parasidis, JD, MBioethics; Professor of Law and Public Health and Faculty Affiliate, Center for Bioethics and Medical Humanities, The Ohio State University.

Presentation: “An Ethical Framework for Health Data”

11:45-1:15 p.m. **Lunch Break**

1:15-2:15 p.m. **Panel 3: Technology and Privacy in Research**

Elonna Ekweani, JD; Public Health Analyst, Office of Science Policy, National Institutes of Health.

Presentation: “Certificates of Confidentiality Following Enactment of the 21st Century Cures Act”

John Wilbanks; Chief Commons Officer, Sage Bionetworks; Senior Fellow, FasterCures.

Presentation: “Participant Centered Design for Informed Consent”

Stacey Tovino, JD, PhD; Judge Jack and Lulu Lehman Professor of Law and Founding Director, Health Law Program, William S. Boyd School of Law, University of Nevada, Las Vegas.

Presentation: “Mobile Application-Mediated Health Research: Privacy and Security Challenges and Opportunities”

Zaev D. Suskin, MBE, MD Candidate; Harvard Medical School Center for Bioethics; Georgetown University School of Medicine.

Presentation: “Mental Privacy Threats when Transitioning New(ro) Technologies from Research Bench to Legal Bench”

2:15-2:30 p.m. **Break**

2:30-3:20 p.m. **Panel 4: Connected Technologies and Data Privacy**

Dianna Carr; Lead Associate, Booz Allen Hamilton.

Presentation: “How Smart is Too Smart? Privacy in a Connected World”

Priya Kumar, PhD Candidate; College of Information Studies (iSchool), University of Maryland, College Park.

Presentation: “Datafication and Privacy Concerns Surrounding the Use of Wearable Fitness Trackers”

Michelle De Mooy, MA; Former Director, Privacy & Data Project, Center for Democracy & Technology.

Presentation: “Heal-gorithms: Understanding the Potential for Bias and Discrimination in mHealth Apps”

3:20-4:10 p.m. **Panel 5: Technological Tools and the Protection of Health Data**

James Del Fiore, JD; Senior Consultant, Booz Allen Hamilton.

Presentation: “Legal and Privacy Considerations of Workplace Wellness Programs and their Devices”

Adrian Gropper, MD; Chief Technology Officer, Patient Privacy Rights Foundation.

Presentation: “Standards for Personal Agency: The Homeless Health Record Project”

Daniel Fabbri, PhD; Assistant Professor, Biomedical Informatics & Computer Science, Vanderbilt University; Founder & CEO, Maize Analytics, Inc.

Presentation: “Risks of ‘Black Box’ Machine Learning in Compliance and Privacy Programs”

4:10-4:15 p.m. **Concluding Remarks**