



HHS Presents “Data Privacy in the Digital Age”: Agenda

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

Thursday, October 26, 2017

- 8:30-9:00 a.m. **Registration**
- 9:00-9:10 a.m. **Opening Remarks and Introduction**
- 9:10-9:20 a.m. **Welcome to Symposium Attendees**
- 9:20-10:20 a.m. **Panel 1: Contemporary Health Privacy Challenges**

Leo Beletsky, JD, MPH; Associate Professor of Law and Health Sciences, School of Law & Bouvé College of Health Sciences, Northeastern University
Presentation: “From Panacea to Panopticon: Privacy and Prescription Drug Monitoring in the Age of the Opioid Crisis”

Kate Black, JD; Privacy Officer and Corporate Counsel, 23andMe, Inc.
Zerina Curevac, JD; Associate, Squire Patton Boggs
Presentation: “A Framework for Notice and Choice in Online Consumer Genetics”

Sharona Hoffman, JD, LL.M., SJD; Professor of Bioethics; Edgar A. Hahn Professor of Law; Co-Director, Law-Medicine Center; Case Western Reserve University School of Law
Presentation: “The HIPAA Security Rule: Strengths and Vulnerabilities”

Kathryn Montgomery, PhD; Professor and Director of the Communication Studies Division, School of Communication, American University
Presentation: “Health Wearables: Ensuring Privacy, Security, and Equity in an Emerging Internet-of-Things Environment”

- 10:20-10:35 a.m. **Break**

10:35-11:25 a.m. **Panel 2: Privacy, Data Sharing, and Research**

Kirsten Ostherr, PhD, MPH; Gladys Louise Fox Professor of English; Director, Medical Futures Lab; Rice University

Presentation: "Trust and Privacy in the Ecosystems of User-generated Health and Medical Data"

Ameet Sarpatwari, JD, PhD; Instructor in Medicine, Harvard Medical School; Assistant Director, Program On Regulation, Therapeutics, And Law (PORTAL)

Presentation: "Data Sharing that Enables Post-approval Drug and Device Research and Protects Patient Privacy: Best Practice Recommendations"

Alexandra Wood, JD, MPP; Fellow, Berkman Klein Center for Internet & Society, Harvard University

Presentation: "Elements of a New Ethical Framework for Big Data Research"

11:25-12:15 p.m. **Keynote Presentation**

Latanya Sweeney, PhD; Professor of Government and Technology in Residence, Department of Government; Faculty Dean, Currier House; Editor-in-Chief, Technology Science; Director, Data Privacy Lab; Harvard University

12:15-1:30 p.m. **Lunch Break**

1:30-2:30 p.m. **Panel 3: Privacy Policy and Regulation**

Idris Adjerid, PhD, MBA; Assistant Professor of Management, Mendoza College of Business, University of Notre Dame

Presentation: "The Impact of Privacy Regulation and Technology Incentives: The Case of Health Information Exchanges"

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

Presentation: "Biometric Data Privacy Problems in Sports: Why the United States Needs a National Privacy Regulator"

Lindsay Gladysz Madejski, JD, CIPP/G; Associate, Booz Allen Hamilton

Presentation: "Privacy and Security Considerations for Evidence Based Policymaking"

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

Presentation: "Ethical and Legal Dimensions of a Risk-based Rubric for Data Privacy"

2:30-2:45 p.m. **Break**

2:45-3:35 p.m. **Panel 4: From Patient to Participant to Specimen to Data: Privacy Across the Health Lifecycle**

Andrew G. Shuman, MD; Assistant Professor, Division of Head and Neck Oncology, Department of Otolaryngology–Head & Neck Surgery, University Michigan Health System; Co-Director, Program in Clinical Ethics; Chair, Adult Ethics Committee and Consultation Service; Center for Bioethics and Social Sciences in Medicine, University of Michigan Medical School; Chief, ENT Section, Surgery Service, VA Ann Arbor Healthcare System

Presentation: “Privacy from Bedside to Laboratory”

Kayte Spector-Bagdady, JD, MBioethics; Assistant Professor, Department of Obstetrics & Gynecology; Chief, Research Ethics Service, Center for Bioethics and Social Sciences in Medicine; University of Michigan Medical School

Presentation: “Dignitary Harms and the Privatization of Data”

Nicolle Strand, JD, MBioethics; Assistant Professor, Bioethics; Assistant Director for Research, Center for Bioethics, Urban Health, and Policy; Lewis Katz School of Medicine at Temple University

Presentation: “Power and Privacy in Data and Biospecimen Research”

3:35-4:25 p.m. **Panel 5: Privacy-preserving Tools, Technologies, and Methodologies**

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

Presentation: “Blockchain-linked Self-sovereign Technology for Information Sharing”

Abel Kho, MD, MS; Associate Professor, Northwestern University Feinberg School of Medicine

Presentation: “Pragmatic Real World Applications of Privacy-preserving Record Linkage”

Bradley Malin, PhD; Professor of Biomedical Informatics, Biostatistics, & Computer Science; Co-Director, Ph.D. Program in Big Biomedical Data Science; Co-Director, Center for Genetic Privacy and Identity in Community Settings; Co-Director, Health Data Science Center; Director, Health Information Privacy Laboratory; Vanderbilt University

Presentation: “An Open Source Tool for Game Theoretic Health Data De-identification”

4:25-4:30 p.m. **Concluding Remarks**