

HHS Presents “Data Privacy in the Digital Age”: Panels and Panelists

Location: Humphrey Building
Date: Thursday, October 26, 2017
Time: 8:30am-4:30pm

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”

Panel 2. Privacy, Data Sharing, and Research

Deven McGraw, JD, LL.M.; Deputy Director for Health Information Privacy, Office for Civil Rights; Acting Chief Privacy Officer, Office of the National Coordinator for Health Information Technology; U.S. Department of Health and Human Services

Presentation: TBD

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 at 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”

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”

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: Focusing on patient privacy

Kayte Spector-Bagdady, JD, MBioethics; Research Investigator, Department of Obstetrics & Gynecology; Co-Lead, Program in Research Ethics; Center for Bioethics and Social Sciences in Medicine; University of Michigan Medical School

Presentation: Focusing on bedside conversations about patient privacy

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: Focusing on patient privacy interests in shared data

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”