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Program

May 20

18:00-20:00 Symposium/Workshops Bridging Reception and Birds of a Feather Sessions

May 21

7:30-8:30 Breakfast

8:30-8:40 Opening Remarks

8:40-9:20 Cryptographic Approaches to Privacy (Chair: Dominique Schroeder)

- Efficient Secure Outsourcing of Genome-wide Association Studies [\[PDF\]](#)
Wenjie Lu, Yoshiji Yamada and Jun Sakuma
- Privacy-Preserving Statistical Analysis by Exact Logistic Regression [\[PDF\]](#)
David Du Verle, Shohei Kawasaki, Yoshiji Yamada, Jun Sakuma and Koji Tsuda

9:20-10:20 Invited presentation

- Eliciting patient preferences for data sharing: Are we ready?
Lucilla Ohno-Machado (UC San Diego)

10:20-10:50 Coffee Break

10:50-11:30 Miscellaneous (Chair: Haixu Tang)

- Passing go with DNA sequencing: Delivering messages in a covert transgenic channel [\[PDF\]](#)

Ji Yong Chun, Hyelim Lee and Ji Won Yoon

- Privacy Threats and Practical Solutions for Genetic Risk Tests [\[PDF\]](#)

Ludovic Barman, Mohammed-Taha Elgraini, Jean Louis Raisaro, Erman Ayday and Jean-Pierre Hubaux

11:30-12:30 Measuring Genome Privacy (Chair: Erman Ayday)

- Quantifying Genomic Privacy via Inference Attack with High-Order SNV Correlations [\[PDF\]](#)

Sahel S. Samani, Zhicong Huang, Erman Ayday, Mark Elliot, Jacques Fellay, Jean-Pierre Hubaux and Zoltan Kutalik

- One Size Doesn't Fit All: Measuring Individual Privacy in Aggregate Genomic Data [\[PDF\]](#)

Sean Simmons and Bonnie Berger

- Genomic Privacy Metrics: A Systematic Comparison [\[PDF\]](#)

Isabel Wagner

12:30-13:30 Lunch

13:30-14:30 GenoPri Keynote Address (Chair: Brad Malin)

- [Privacy & Knowing in DTC Genetic Testing](#)

Kate Black, J.D. (Privacy Officer & Corporate Counsel, 23andme)

14:30-15:10 Policy, Law, and Genomic Privacy (Chair: Emiliano De Cristofaro)

- Genomic Privacy and Direct-to-Consumer Genetics [\[PDF\]](#)

Andelka Phillips

- Seeking a "Race to the Top" in Genomic Cloud Privacy [\[PDF\]](#)

Mark Phillips, Bartha M. Knoppers and Yann Joly

15:10-15:40 Coffee Break

15:40-17:10 Panel (Moderator: Xiaoqian Jiang)

- Genomic privacy threat and risk measurement

Jean-Pierre Hubaux, Yong Li, Amalio Telenti, Haixu Tang

17:10-17:20 Closing Remarks

Keynote: Privacy & Knowing in DTC Genetic Testing, Kate Black, J.D. (Privacy Officer & Corporate Counsel, 23andme)

Abstract

The use of DTC genetics in research and data analysis is a rapidly growing and complex field. Progress made in this arena allows genomic testing to potentially detect, specifically treat, and study various types of disease. Genetic discoveries can also answer research questions relating to issues such as population trends, migration patterns and the like. In addition, individuals benefit from their own genetic information through knowledge gained and by sharing the information contained in their genomic data with family, friends, and caregivers, if they so choose. But the potential rewards from genetic testing is not without privacy risks, including:

- The possibility of researchers deducing the identity of genetic donors through their DNA
- Third party access to information
- Implementing enough security safeguards to protect such unique and sensitive information

Appropriately balancing the myriad benefits of genetic information with the privacy of individuals is at the heart of emerging legal and policy challenges in genetic privacy. However, a legal and regulatory environment to support this new and unique type of analysis and research has not yet fully developed. Instead, a patchwork of state and federal laws protect some portions of the information from certain uses, and are highly dependent on who is holding and controlling the genetic information.

What you'll take away:

- Emerging legal and ethical issues in DTC genetic testing, research, and analysis
- Challenges and risks in protecting the privacy of genetic information in the online world

Kate joined 23andMe in 2015 in the newly created role of privacy officer and corporate counsel. Her responsibilities include: developing, implementing, overseeing, and maintaining comprehensive privacy and data use policies, practices and procedures for the company. Prior to 23andMe, Kate spent two years with the U.S. Department of Health and Human Services' Office of the National Coordinator for Health IT (ONC) where she was responsible for developing and updating national privacy and security requirements. Before ONC, she was staff attorney for the Health Privacy Project at the Center for Democracy and Technology (CDT).

Kate holds a Juris Doctorate from The George Washington University and received a bachelor of science degree in health sciences from The Florida International University.

