

# 7<sup>th</sup> International Summit on the Future of Health Privacy: *Is Health Privacy a Human Right?*

### AGENDA DAY 1 - Thursday, June 1, 2017

McDonough Hall, Hart Auditorium, Georgetown Law Center 600 New Jersey Ave. NW, Washington, DC 20001

7:45 – 8:30 am	Registration   Light Breakfast
8:30 – 8:50 am	Opening Session: From Hippocrates to Human Rights
0.00 0.00 0	Deborah C. Peel   Founder and President, Patient Privacy Rights
8:50 - 9:35 am	Keynote: The GDPR and the European Vision for the Future of the Digital World
	Isabelle Falque-Pierrotin   President, French Data Protection Authority (CNIL) and Chair, European Union's Article 29 Working Party
9:40 – 10:25 am	Keynote: Autonomy. Dignity. Freedom. European Approaches to Data Protection in Medical Research and Treatment
	Nikolaus Forgó   Professor of Law, Chief Information Officer, Privacy Officer, and Co-Director of the Institute for Legal Informatics at Leibniz Universität Hannover
10:25 – 10:40 am	Break
10:40 – 11:30 am	Session 1: The EU's General Data Protection Regulations and its Impact on the U.S.
	Moderator Shahid Shah   Chief Executive Officer, Netspective Communications
	Speakers
	Gary LaFever   Chief Executive Officer, Anonos and former Partner, Hogan Lovells Anna Spencer   Partner, DLA Piper
	Stacey A. Tovino   Lehman Professor of Law and Founding Director, UNLV Health Law Program, William S. Boyd School of Law, University of Nevada, Las Vegas
11:35 – 12:25 pm	Session 2: Health Privacy in the LGBTQIA Community, Electronic Health Records Systems and Sensitive Data
	Moderator
	Kellan Baker   Senior Fellow, Center for American Progress  Speakers
	Trevor Hoppe   Assistant Professor, University of Albany, SUNY
	Amy E. Nelson   Director of Legal Services, Whitman-Walker Health
12:25 – 1:25 pm	Lunch
1:25 – 2:10 pm	Fireside Chat: Blockchain Technology and Health Data: How it works, what can it add, and what's all the hype about?
	David Huseby   Security Maven, The Linux Foundation's Hyperledger Project
2:15 – 3:05 pm	Session 3: Breakouts
Hart Auditorium	3a. State Health Databases: Re-identification of patient records and expansion of the DataMap
	Becina Ganther   Student, Harvard University Harshita Gupta   Student, Harvard University
	Alexandra Thaler   Student, Harvard University
	Ji Su Yoo   Research Assistant, Harvard University's Institute for Quantitative Social Science
Room 200	3b. Workplace Wellness and Employee Genetic Testing: Should employers and insurers have access to genetic tests?
	Moderator
	Ifeoma Ajunwa   Assistant Professor, Cornell University's ILR School and Fellow, Harvard University's Berkman Klein Center
	Speakers  Kate Black   Privacy Officer and Corporate Counsel, 23andMe
	Michelle De Mooy   Data and Privacy Project Director, Center for Democracy and Technology

William F. Pewen | Consultant and Author



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#### AGENDA DAY 1 Continued - Thursday, June 1, 2017

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3:05 - 3:15 pm Break

3:15 – 4:05 pm **Session 4: Breakouts** 

Hart Auditorium 4a. Patients' use of Health Information Exchanges: Do they care? Can they get personal health data? How do they use it?

Moderator

Thomas Welch | Managing Director, American International Regulatory Coherence Institute and Attorney and Counsellor, Thomas Welch Law

Speakers

Randy Farmer | Chief Operating Officer, Delaware Health Information Network

Adrian Gropper | Chief Technology Officer, Patient Privacy Rights

Josh Mandel | Health IT Ecosystem Lead, Verily (Google Life Sciences)

Glenn Tucker | Chief Medical Information Officer and Chief of Internal Medicine, Sturdy Memorial Hospital and

Chairman, Massachusetts Medical Society's Committee on IT

4b. Recent Empirical Research on Health Privacy: Do young people care about health privacy? Is compelled disclosure of health information a major privacy issue?

Mark A. Rothstein | Herbert F. Boehl Chair of Law and Medicine and Director of the Institute for Bioethics, Health Policy and Law, University of Louisville School of Medicine

4:10 – 4:55 pm Keynote: Augmenting Human and Machine Intelligence to Improve Medical Care

Vikash Mansinghka | Research Scientist and leader of the Probabilistic Computing Project, MIT

4:55 – 5:05pm Closing Remarks

Deborah C. Peel | Founder and President, Patient Privacy Rights



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#### AGENDA DAY 2 - Friday, June 2, 2017

McDonough Hall, Hart Auditorium, Georgetown Law Center 600 New Jersey Ave. NW, Washington, DC 20001

7:45 - 8:30 am **Light Breakfast** 8:30 - 8:45 am Welcoming Kurt Long | Chief Executive Officer and Founder, FairWarning 8:45 - 9:45 am Keynote: An Overview of Technology and the Health System John Fleming | Deputy Assistant Secretary for Health Technology Reform, HHS 9:50 - 10:40 am Session 1: Delivering Healthcare in the Age of Artificial Intelligence Nikolaus Forgó | Professor of Law, Chief Information Officer, Privacy Officer, and Co-Director of the Institute for Legal Informatics at Leibniz Universität Hannover Speakers John Havens | Executive Director, IEEE Global Initiative for Ethical Considerations in Artificial Intelligence and **Autonomous Systems** Kurt Long | Chief Executive Officer and Founder, FairWarning 10:40 - 10:55 am 10:55 - 11:45 am Session 2: Breakouts Hart Auditorium 2a. How Private are Your Prescriptions? The Importance of Access Restrictions for PDMPs Nathan Freed Wessler | Speech, Privacy, and Technology Project Staff Attorney, ACLU Speakers Mark Greenblatt | Senior National Investigative Correspondent, Scripps Washington Bureau Lisa Matsubara | Legal Counsel, California Medical Association's Center for Legal Affairs Ryan Pyle | Utah Firefighter Room 200 2b. What's new with the Data Map: Tracking flows of personal information Latanya Sweeney | Professor of Government and Technology and Director of the Data Privacy Lab, Harvard University 11:45 - 12:00 pm **Break LUNCHEON & CLOSING PLENARY** Gewirz Student Center, 12th floor - Georgetown University Law Center 12:00 - 1:15 pm Companies Competing for Privacy: Has privacy innovation begun? Moderator Nikolaus Forgó | Professor of Law, Chief Information Officer, Privacy Officer, and Co-Director of the Institute for Legal Informatics at Leibniz Universität Hannover

Speakers

Clint Phillips | Chief Executive Officer and Founder, Medici and 2nd.MD

Julian Ranger | Executive Chairman and Founder, digi.me

Doc Searls | Journalist, Author of The Intention Economy, and Co-author of The Cluetrain Manifesto

**Closing Remarks** 

1:15 - 1:30 pm Deborah C. Peel | Founder and President, Patient Privacy Rights