

7th 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
	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 Kay Firth-Butterfield | Vice Chair, IEEE Global Initiative for Ethical Considerations in Artificial Intelligence and Autonomous Systems and Executive Director, Al-Austin Speakers Nikolaus Forgó | Professor of Law, Chief Information Officer, Privacy Officer, and Co-Director of the Institute for Legal Informatics at Leibniz Universität Hannover 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 Break 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 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 Ted Kim | Chief Executive Officer, London Trust Media 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 1:15 - 1:30 pm **Closing Remarks**

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