Agenda

1:15 p.m. – 2:10 p.m.	**Session 3: "Big Data — More Information & More Risks"** *Moderator*: James Koenig, Co-Leader, Health Information Privacy & Security Practice, PricewaterhouseCoopers *Panel*: Cathy Betz, Source Healthcare Analytics; Debra Bromson, AstraZeneca Pharmaceuticals LP; Corinne Carey, NYCLU; Kurt Long, FairWarning®; Mark Rothstein, U. of Louisville School of Medicine
2:10 p.m. – 2:25 p.m.	**Session 3: Q & A**
2:25 p.m. – 2:40 p.m.	*15-Minute Break*
2:40 p.m. – 3:40 p.m.	**Session 4: Introduction to Summit Workgroups:** • Technology Solutions: Andrew Blumberg & Lee Tien • Consumer Education: Kathryn Serkes & David Wanser • Principles: Michelle DeMooy & James Pyles
3:45 p.m. – 4:40 p.m.	**Best Privacy Technologies of 2012** Demonstrations of successful, implemented technologies that enhance patient control over personal health information
4:40 p.m. – 5:10 p.m.	**Closing Keynote** Ross Anderson, PhD Professor in Security Engineering University of Cambridge Computer Laboratory
5:10 p.m. – 5:20 p.m.	**Wrap Up** David Hilgers, Partner, Brown McCarroll, LLC Deborah C. Peel, MD, Patient Privacy Rights

Please proceed to the *Washington Court Hotel* for the Celebration of Privacy
525 New Jersey Avenue, NW, Washington, DC 20001

Celebration of Privacy

6:00 p.m. – 8:00 p.m.	**Presentation of theDataMap.org** Latanya Sweeney, PhD *A project of the Harvard Data Privacy Lab & Patient Privacy Rights* **Presentation of the First Louis D. Brandeis Privacy Awards**

Agenda

Thursday, June 7, 2012

8:00 a.m. – 8:10 a.m.	**Introduction** Deborah C. Peel, MD, Patient Privacy Rights
8:10 a.m. – 9:10 a.m.	**Session 1** **Docs & EHRs. How is the Physician-Patient Relationship Affected?** *Moderator*: Michael Stearns, MD, CEO, e-MDs *Panel*: H. Westley Clark, SAMHSA; Andrew Litt, Dell, Inc.; Fausto Meza, Doctors Hospital at Renaissance; Scott Monteith, Michigan State University; CAPT Michael Weiner, Defense Systems
9:15 a.m. – 10:10 a.m.	**Issues Sessions** See Next Page
10:10 a.m. – 10:25 a.m.	*10-Minute Break*
10:25 a.m. – 11:20 a.m.	**Repeat of Issue Sessions** See Next Page
11:25 a.m. – 12:15 p.m.	**Work Group Sessions & Attendee Participation** • Technology Solutions: Andrew Blumberg & Lee Tien • Consumer Education: Kathryn Serkes & David Wanser • Principles: Michelle DeMooy & James Pyles

Please proceed to the *Washington Court Hotel* for the Seated Lunch Panel
525 New Jersey Avenue, NW, Washington, DC 20001

12:30pm - 1:40pm	Seated Lunch Panel **"Cultural Perspectives on Religion & Privacy"** *Moderator*: Steven Mosher, President, Population Research Institute

Issue Session Topics

"How Do Ideal Patient-Centered, Ethically Based Health IT Systems Address Privacy?"

Models of ideal, trustworthy, ethical, patient-centered health care systems will be presented followed by discussion and Q&A with the audience.

Moderator: Mark Rotenberg, EPIC

Panel: Ross Anderson, University of Cambridge Computer Laboratory; Latanya Sweeney, Harvard Data Privacy Lab

"Health Information Privacy & Health IT - Where Are We and How Did We Get Here?"

This session will be a mini-course on state and federal health privacy laws and regulations, common law, tort law, and Constitutional decisions that shape Americans' rights to health information privacy.

Course Leader: James Pyles, Powers Pyles Sutter & Verville

"HIEs: What We Know and Don't Know, Data Segmentation & Patient-Centered Options (e.g., opt-in/opt-out)"

This session will deal with actions to implement health data exchange and their effects on privacy. The panel will discuss the best & worst ways the mandate for data exchange is being implemented.

Moderator: Robert Kolodner, Co-Founder & Pres., Collaborative Transformations, LLC; Executive Vice President & Chief Health Informatics Officer, Open Health Tools, Inc.

Panel: Corinne Carey, NYCLU; SAMHSA; Romulo Juarez, Accenture; Mark Rothstein, U. of Louisville School of Medicine; COL John Scott, OASD; David Staggs, Jericho Systems; Richard Thoreson, SAMHSA

"Is Genetic Privacy Threatened?"

Are the special protections in state and federal law effective against the use of genetic data by health insurers and employers? Is genetic data more sensitive or more valuable than other health data? The panel will explore how genetic data privacy is challenged by the collection and biobanking of samples, the sale and use of genetic data, attachment of genetic information to EHRs, and increased collection and use of genetic outside of healthcare.

Moderator: Bill Sage, University of Texas at Austin

Panel: Ed Abrahams, Personalized Medicine Coalition; Ann Cook, NIH Researcher; Jeremy Gruber, Council for Responsible Genetics; Linda Rodriguez, NIH; Kathryn Serkes, Doctor Patient Medical Association

"How do Social Media, Mobile Devices, Medical Devices and Implants, Online 'Health Websites,' and Clouds Threaten Health Privacy?"

The panel will discuss how new technologies, many of which are outside of the healthcare system, further erode individual control over the use personal health information.

Moderator: Steve Steffensen, TATRC

Panel: Adrian Gropper, Health URL.com; Deven McGraw, CDT;Jon Neiditz, Nelson Mullins Riley & Scarborough; Lee Tien, EFF; Nicolas Terry, IU McKinney School of Law