

2nd International Summit on the Future of Health Privacy



healthprivacysummit

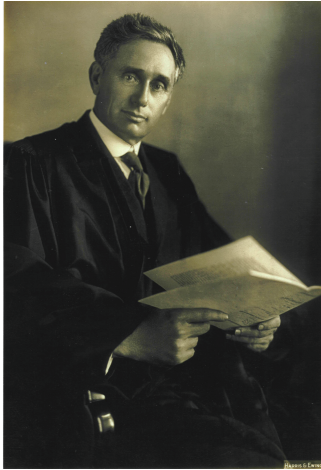
June 6 & 7, 2012
Washington, D.C.

Is there an American Health Privacy Crisis?

O'NEILL
INSTITUTE
FOR NATIONAL & GLOBAL HEALTH LAW

GEORGETOWN LAW

patientprivacyrights



The Louis D. Brandeis Privacy Award

"The right to be let alone is the most comprehensive of rights and the right most valued by civilized men."

-Justice Brandeis, 1928, Olmstead v. United States, dissenting

In 1890, Louis D. Brandeis co-authored what has historically been called "the most influential law review article of all," *The Right to Privacy*. As a Supreme Court Justice from 1916-1939, he changed the nation's and the world's understanding and appreciation for privacy as the foundation of the individual, civil, and human rights that underlie all democracies. Brandeis often joined his colleague, Oliver Wendell Holmes, Jr., in dissenting against the Court's willingness to pose its judgments about economic and social policy against those of individual states. With Holmes, Brandeis bravely defended civil liberties throughout his era. If he did uphold wide use of state powers, it was only in the service of furthering individual self-fulfillment; he also rejected incursions of a state upon a citizen's liberty. Two examples are the Olmstead case (already noted), involving wiretapping, and Whitney v. California in which Brandeis opposed a California law suppressing free speech.

The first Louis D. Brandeis Privacy Awardees are being recognized for their significant intellectual, legal, and technical contributions to the field of health information privacy. Standing on the shoulders of Supreme Court Justice Louis D. Brandeis, these heroes work to ensure that the "highest right of civilized man" remains the foundation for all electronic systems and for law and policy governing the use and control of sensitive health information.

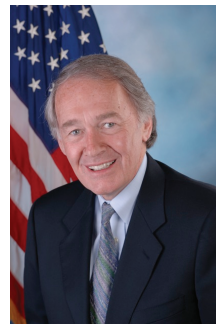
2012 Louis D. Brandeis Privacy Awardees



Ross Anderson, PhD
Professor in
Computer Engineering
University of Cambridge
Computer Laboratory



**The Honorable
Joe Barton**
Congressman
6th District
of Texas



**The Honorable
Ed Markey**
Congressman
7th District of
Massachusetts



Alan Westin, PhD
Of Counsel & Senior Policy
Advisor, Arnall Golden
Gregory, Atlanta &
Washington DC

Awards to be presented at the Celebration of Privacy, the evening of June 6, 2012
6:00 p.m. – 8:00 p.m. at the Washington Court Hotel

Dear Friends,

On behalf of Georgetown University and the O'Neill Institute for National and Global Health Law, it is my great pleasure to welcome you to the 2nd International Summit on the Future of Health Privacy.

Privacy is among the greatest challenges facing America and all democracies that care about the dignity and well being of their people. The health system collects, stores, and widely disseminates unimaginable amounts of personal information—in health insurance, medical practices, hospitals, and public health agencies. These data can be used for the public's good such as in research, quality assurance, and population health. But unless we maintain reasonable assurances of privacy, the unauthorized disclosure of health information can result in stigma, discrimination, and great harm. This 2nd International Summit on the Future of Health Privacy brings us together to think, research, and act on the need for health informational privacy. Georgetown Law and the O'Neill Institute are proud to join with our partner, Patient Privacy Rights, to host this vital meeting.



This Summit represents an integral part of the O'Neill Institute's mission to discover innovative solutions to the most pressing health concerns facing the nation and the world. The essential vision for the O'Neill Institute rests upon the proposition that the law has been, and will remain, a fundamental tool for solving critical health problems in our local, national, and global communities. By contributing to a more powerful and deeper understanding of the multiple ways in which law can be used to improve health, the O'Neill Institute hopes to encourage key decision-makers in the public, private, and civil society sectors to employ the law as a positive tool to enable individuals and populations in the United States and throughout the world to lead healthier lives.

The 1st International Summit on the Future of Health Privacy was held in the summer of 2011 here at Georgetown Law, as collaboration between Patient Privacy Rights and the Lyndon B. Johnson School of Public Affairs at the University of Texas. Dr. Deborah Peel has worked tirelessly to address this critical issue facing our nation's health systems.

We greatly look forward to hearing your ideas over the next couple of days, in hopes that you can help us identify how we can shape health IT development to be socially responsible and ethical in addition to its practical applications.

To close, let me thank Deborah Peel and Patient Privacy Rights, along with our distinguished guests and all of our generous sponsors, for helping to make this forum a continuing dialogue for progress.

Regards,

A handwritten signature in black ink that reads "Lawrence O. Gostin". The signature is written in a cursive, flowing style.

Lawrence O. Gostin
Faculty Director, O'Neill Institute for National and Global Health Law
University Professor, Georgetown University
Linda and Timothy O'Neill Professor of Global Health Law, Georgetown Law

Welcome



Dear Friends,

Patient Privacy Rights and the bipartisan Coalition for Patient Privacy, representing 10.3 million Americans welcome you to the 2nd International Summit on the Future of Health Privacy.

This is truly an historic event. Last year proved there is broad support for open public dialogue about ways to restore and strengthen privacy and individuals' rights to control the use of personal health information in electronic systems.

Once more, the 2nd Summit will create a platform for thoughtful dialogue about privacy. We will examine whether or not America is facing a health privacy crisis and ask serious questions about the current state of health information technology. A richer view of the complex and dynamic US healthcare and health IT systems that are accumulating unimaginable volumes of data will result. To gain insight into the entire ecosystem, we will identify the various stakeholders who often have opaque conflicts of interests and wear multiple hats. One thing we know for certain is this: without facing reality and without including the voices of patients — the legal, cultural, and innovative changes needed for trust and privacy will not happen.

We have extended this year's Summit to allow more time for rich discussions on the subject of health privacy. In addition to featuring the three "Best Privacy Technologies of 2012," we will hold the inaugural "Celebration of Privacy" to announce the DataMap.org project and to honor the first recipients of the Louis D. Brandeis Privacy Awards.

Yet again, you will see, hear, and actively engage with some of the world's greatest experts as they discuss the hard problems that we must work together to solve. We are deeply gratified that such a diverse group of individuals has come together to lay out major privacy issues and discuss effective, realistic solutions that ensure people's willingness to see doctors and participate in electronic health systems.

I would like to thank our academic partners this year. They include the Harvard Data Privacy Lab, RTI International, the University of Cambridge Computer Laboratory, the University of Texas School of Information, and the O'Neill Institute for National and Global Health Law at Georgetown Law Center. In particular, I want to express our thanks to Larry Gostin for being our generous host and contributing so significantly to the success of this year's Summit.

Privacy is a work in progress. We must identify and strive for ideal solutions, but we are human. Perfection is not achievable, but realistic, effective solutions are. Identifying the flaws in electronic health systems and working to close the gaps in the laws and policies that govern them attracts others to join this community. With this knowledge they can contribute to furthering two great and noble causes: 1) ensuring the privacy that enables patients to talk to and trust physicians and health professionals, and 2) preserving the right to privacy that underlies Democracy and our precious freedoms.

We are eager to move forward together...

A handwritten signature in black ink, which appears to read "Deborah C. Peel". The signature is fluid and cursive, with a long horizontal line extending to the right.

Deborah C. Peel, MD
Founder & Chair
Patient Privacy Rights



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Special Thanks to the Academic Partners of the
2nd International Summit on the Future of Health Privacy:

The O'Neill Institute for National &
Global Health Law at Georgetown Law

Harvard Data Privacy Lab

RTI, International

The University of Cambridge Computer Laboratory

The University of Texas School of Information

Agenda

Wednesday, June 6, 2012

Hart Auditorium, McDonough Hall
Georgetown University Law Center
600 New Jersey Avenue, NW
Washington, DC 20001

- 8:15 a.m. – 8:25 a.m. **Introduction**
Lawrence O. Gostin, O'Neill Institute for National & Global Health Law
Deborah C. Peel, MD, Patient Privacy Rights
- 8:25 a.m. – 9:15 a.m. **Keynote: "Creating a Culture of Privacy & Security Awareness"**
Farzad Mostashari, MD
National Coordinator for Health IT, Health & Human Services
- 9:20 a.m. – 9:45 a.m. **Patient Stories About Privacy Loss**
- 9:50 a.m. – 10:45 a.m. **Session 1: "First Do No Harm. Does Technology Harm Patients?"**
Moderator: Andrew Dillon, Dean, School of Information, U. Texas at Austin

Panel: Lillie Coney, EPIC; Ann Cook, NIH; Maneesha Mithal, FTC; Pablo Molina, Georgetown Law; John Sabo, Computer Associates; William Sage, UT Austin
- 10:45 a.m. – 11:00 a.m. **Session 1: Q & A**
- 11:00 a.m. – 11:15 a.m. *15-Minute Coffee Break*
- 11:15 a.m. – 12:10 p.m. **Session 2: "Is There Too Much or Too Little Regulation? Will States or Congress Regulate?"**
Moderator: Barry Chaiken, former Board of Directors Chair, HIMSS

Panel: Frank Pasquale, Seton Hall Law School; Joy Pritts, ONC/HHS; James Pyles, PPSV; Marcy Wilder, Hogan Lovells
- 12:10 p.m. – 12:25 p.m. **Session 2: Q & A**
- 12:25 p.m. – 1:15 p.m. *Lunch*

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



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Best Privacy Technologies of 2012

This award will be presented to the three best technologies that demonstrate innovative capabilities in support of health privacy.

Examples of key capabilities, include:

- Enabling patient control of personal information
 - Securing patient information
- Minimizing the harm to patients in the event of a breach

Recipients To Be Announced During the Afternoon Session

Featured Speakers

Ross Anderson, PhD

University of Cambridge Computer Laboratory

Ross Anderson is Professor of Security Engineering at Cambridge University. He has been involved in medical safety and privacy for many years, having been an adviser to the British Medical Association and the Icelandic Medical Association in the mid-1990's; chair of the Foundation for Information Policy Research, the UK's leading internet-policy think-tank, since 1998; and a Special Adviser to the UK Health Committee's inquiry into the Electronic Patient Record.

Farzad Mostashari, MD, ScM

National Coordinator for Health Information Technology, Department of Health and Human Services

Farzad Mostashari, MD, ScM, serves as National Coordinator for Health Information Technology at the U.S. Department of Health and Human Services. Previously, he served at the New York City Department of Health and Mental Hygiene as Assistant Commissioner for the Primary Care Information Project. He also led the Centers for Disease Control and Prevention (CDC), funded NYC Center of Excellence in Public Health Informatics, an Agency for Healthcare Research and Quality funded project focused on quality measurement at the point of care, and established the Bureau of Epidemiology Services at the NYC Department of Health.

Latanya Sweeney, PhD

Director & Founder, Harvard Data Privacy Lab

Latanya Sweeney, PhD has made a career of weaving technology and policy together. Dr. Sweeney has made numerous discoveries related to identifiability and privacy technologies and she has had significant impact on American privacy policy. Dr. Sweeney's work has appeared in hundreds of news articles, numerous academic papers, was cited in the original publication of the HIPAA Privacy Rule and was praised in the TAPAC Report that reviewed the Total Information Awareness Project of DARPA. She has also testified before the Privacy and Integrity Advisory Committee of the Department of Homeland Security and the European Union Commission. Companies have licensed and continue to use her privacy technologies. Dr. Sweeney is a Visiting Professor and Scholar at Harvard University, was a Distinguished Career Professor of Computer Science, Technology and Policy in the School of Computer Science at Carnegie Mellon University, and remains the Director and founder of the Data Privacy Lab, now at Harvard University.

All Summit Speakers

Edward Abrahams, PhD

President of Personalized Medicine Coalition

Dr. Abrahams, currently the President of Personalized Medicine Coalition, has served as Executive Director of the Pennsylvania Biotechnology Association and as Assistant Vice President for Federal Relations at the University of Pennsylvania. Dr. Abrahams also has extensive experience in the U.S. Congress and has published numerous essays. Dr. Abrahams now serves as senior editor of Personalized Medicine.

Cathy Betz, JD, MHA

Vice President, Government Affairs

Source Healthcare Analytics, a Symphony Health Solutions company

Cathy Betz is responsible for developing and executing Source Healthcare Analytics' (formerly Wolters Kluwer Pharma Solutions) government affairs strategy which is designed to educate and inform federal and state legislators and other interest groups on health policy issues of interest to the company's various business enterprises. A well respected advocate and spokesperson on health policy and health law issues, Ms. Betz brings over 25 years of legislative and government affairs experience to this role, including policy development, legislative and regulatory analysis, stakeholder relations and consensus building. Joining the company in 2007, Ms. Betz is based in Washington D.C. She holds a BS from James Madison University, a Juris Doctor from George Mason University's School of Law, and a Master's in Health Administration from the Medical College of Virginia, Virginia Commonwealth University.

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Andrew Blumberg, PhD

Assistant Professor of Mathematics at University of Texas at Austin

Dr. Blumberg is an assistant professor of mathematics at UT-Austin. His primary research focus is algebraic topology, but he has also worked on the design of practical privacy-preserving systems for locational privacy and has extensive experience as a software engineer. He became involved in technology questions surrounding electronic health records more recently, as part of work with PPR.

Corinne Carey, JD

Senior Public Policy Counsel, New York Civil Liberties Union

A longtime drug law reform and harm reduction advocate, Corinne Carey was a founding member of Prevention Point Philadelphia, the city's first needle exchange program. She serves on the board of directors of National Advocates for Pregnant Women, and has spoken about the rights of drug users to local, national and international audiences. Prior to joining the NYCLU, Ms. Carey was a researcher with the U.S. Program at Human Rights Watch.

Barry Chaiken, MD, MPH, FHIMSS

Former Chairman of the Board of the HIMSS, Imprivata

Barry P. Chaiken, MD, MPH, FHIMSS, has over 20 years of experience in healthcare information technology, patient safety, clinical transformation, and public health. During his career, he has worked with the National Institute of Health, U.K.'s National Health Service, McKesson, and BearingPoint.

H. Westley Clark, MD, JD

Director, Center for Substance Abuse Treatment, SAMHSA

As director of the Center for Substance Abuse Treatment under the Substance Abuse and Mental Health Services Administration, U.S. Department of Health and Human Services, Dr. H. Westley Clark leads the agency's efforts to provide effective and accessible treatment to all Americans with addictive disorders. Dr. Clark's areas of expertise include substance abuse treatment, methadone maintenance, pain management, dual diagnosis, psychopharmacology, anger management, and medical and legal issues.

Lillie Coney

Associate Director of Electronic Privacy Information Center (EPIC)

Lillie Coney is associate director of the Electronic Privacy Information Center (EPIC) in Washington, D.C., where her work encompasses forecast and analysis of emerging technology and government policy and its implications for privacy. In 2009, House Speaker Nancy Pelosi appointed Ms. Coney to the Election Assistance Commission Board of Advisors. Ms. Coney also co-chaired the 2011 Computers Freedom and Privacy Conference: The Future is Now, and chaired the Public Voice Conferences in 2010 and 2011.

Ann Freeman Cook, PhD

Research Professor in the Department of Psychology, and Director of the National Rural Bioethics Project at the University of Montana

Ann Freeman Cook, PhD., a professor at the University of Montana, serves as an ethics consultant and has been the principal investigator for empirical, interdisciplinary ethics research studies that have been supported by numerous organizations. Dr. Cook's current body of research is exploring the alignment of understanding among IRB members, investigators, and research participants when approving, conducting, or participating in clinical trial research in more rural areas of the US.

Andrew Dillon, PhD

Dean, University of Texas at Austin School of Information

Andrew Dillon has been an active researcher of the human response to information technology for the last 20 years. He was appointed Research Fellow at the Human Sciences & Advanced Technology Research Institute in the UK and has published more than 100 articles and books on various aspects of human information behavior and design. Dean Dillon serves or has served on the editorial boards of many leading journals such as the International Journal of Human-Computer Studies, Interacting with Computers, and the Journal of Documentation.

Lawrence O. Gostin, JD

Faculty Director, O'Neill Institute for National & Global Health Law; University Professor, Georgetown University; Linda D. and Timothy J. O'Neill Professor of Global Health Law, Georgetown Law

Lawrence O. Gostin, an internationally acclaimed scholar, is the Linda D. and Timothy J. O'Neill Professor of Global Health Law at the Georgetown University Law Center, where he directs the O'Neill Institute for National and Global Health Law. Professor Gostin is the Director of the World Health Organization Collaborating Center on Public Health Law and Human Rights. He is also Professor of Public Health at the Johns Hopkins University and Director of the Center for Law & the Public's Health at Johns Hopkins and Georgetown Universities.

Adrian Gropper, MD

Principal, HealthURL.com

Dr. Gropper is a pioneer in patient-centered and patient-controlled health records on the Internet. In 1995, Dr. Gropper founded AMICAS (NAS:AMCS) as the first Web-based radiology PACS and the first to provide direct links to diagnostic imaging in electronic health records. Dr. Gropper also founded MedCommons in 2004 to develop software for image-enabled, patient-centered health records supporting all of a patient's caregivers. He also serves on the Massachusetts Health Information Exchange Technology Workgroup panel, among others.

Jeremy Gruber, JD

President, Council for Responsible Genetics

Jeremy Gruber, JD, is the President of the Council for Responsible Genetics. Mr. Gruber is an expert on issues of genetic privacy and discrimination. He has worked for over fifteen years on genetic non-discrimination legislation at the state level and was a leader of the successful effort to pass the Genetic Information Non-Discrimination Act (GINA). He is a founder and executive committee member of the Coalition for Genetic Fairness, a group of 500 organizations that advocates for genetic non-discrimination protections on Capitol Hill. Additionally, Mr. Gruber writes extensively on a range of genetics policy issues and is often consulted by and called to testify before Congress, Federal agencies, and state legislatures.

David W. Hilgers, JD

Partner, Brown McCarroll, L.L.C.

David W. Hilgers is a Partner at Brown McCarroll, L.L.P. and is a member of the firm's Health Care Law Section. He has practiced law for more than thirty-five years. His primary focus is on health care, corporate, and administrative law. Mr. Hilgers represents healthcare providers, including physicians, dentists, healthcare systems, managed care organizations, long-term care facilities, multi-specialty groups, hospitals, hospital districts, and community mental health and mental retardation centers.

The Honorable Tim Huelskamp (Invited)

Congressman, 1st District of Kansas

Congressman Tim Huelskamp was elected to his first term as a United States Representative in November 2010. In the 112th Congress he represents Kansas' First Congressional District, known as the "Big First." Congressman Huelskamp attended a seminary in Santa Fe, New Mexico and pursued his bachelor's degree in social science education at the College of Santa Fe. After his undergraduate education, Congressman Huelskamp accepted a scholarship to pursue doctoral studies at The American University in Washington, D.C. In four years he obtained a PhD in Political Science with a specialization in agriculture policy.

Romulo Juarez

Senior Executive of Accenture EMR Transformation Group

Romulo Juarez has been providing leadership to the top 150 healthcare organizations and the US Government for twenty years. He has focused expertise in the client-partner role, managing clients within healthcare across Provider, Payer and Health Information Exchange industries and has led core strategies and implementations supporting Patient Safety and Meaningful Use requirements. Mr. Juarez is active and provides leadership within HIMSS, specifically the development of HIE and burgeoning HIX market solutions.

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Jim Koenig, CIPP

Practice Leader, Privacy Strategy & Compliance, Security Co-Leader, HIT Practice PricewaterhouseCoopers, LLP

Jim Koenig is a Director and Leader of PricewaterhouseCoopers' Privacy and Identity Theft practice. He has an extensive business, technology, and legal background, and is a recognized authority on privacy issues impacting healthcare, financial services, direct marketing and technology. Jim provides global privacy and security strategy, compliance, and training services focused on ROI-driven solutions that balance the goals of business with respect for consumer privacy.

Robert M. Kolodner, MD

Co-founder and President, Collaborative Transformations, LLC

Executive Vice President & Chief Health Informatics Officer for Open Health Tools, Inc. (OHT)

Robert M. Kolodner, MD, has prestigious positions at Collaborative Transformations, LLC, as well as Open Health Tools, Inc. (OHT), a multinational, non-profit organization dedicated to improving the health of people through the transformation of health information technologies (IT) for personal health, health care delivery, and population health. In these two roles, Dr. Kolodner is continuing his work to improve the health and well-being of individuals and communities worldwide by facilitating the widespread use and rapid, collaborative evolution of health IT tools and solutions.

Dr. Kolodner's 31 years of Federal service and leadership include serving as the National Coordinator for Health IT, the President's designated lead for the United States eHealth initiatives, and a key leadership position in the VA that led to the world's first successful large-scale Electronic Health Record implementation.

Andrew W. Litt, MD

Chief Medical Officer at Dell Healthcare & Life Sciences

Dr. Andrew Litt helps global health care providers achieve an environment that is interconnected, efficient and patient-focused. He helped found CareCore National, a company that provides utilization and quality management programs for managed care company clients and was a founding board member of Imaging on Call, a company that provides emergency radiology practices via the internet.

Kurt J. Long

Founder & Chair, FairWarning®

Kurt Long is the Founder and CEO of FairWarning, Inc., the inventor and global leader in privacy breach detection solutions for electronic health records. In 1995, Mr. Long founded and subsequently served as CEO of OpenNetwork Technologies, a leader in web single sign on and identity management software solutions. At the outset of his career, Mr. Long held positions of growing responsibility with Lockheed Space Operations at Kennedy Space Center and IBM. Mr. Long is a recognized industry expert in the "AAA" security industry (Authentication, Authorization, Audit) and has authored dozens of published articles on the topic.

Deven McGraw, JD

Director of the Health Privacy Project, Center for Democracy & Technology

Ms. McGraw is active in efforts to advance the adoption and implementation of health information technology and electronic health information exchange to improve health care. She was one of three persons appointed by the Secretary of the U.S. Department of Health & Human Services (HHS), to serve on the Health Information Technology (HIT) Policy Committee and also served on two key workgroups of the American Health Information Community (AHIC).

Fausto S. Meza, MD, MPA

Chief Medical Information Officer, Doctors Hospital at Renaissance

Fausto S. Meza, MD, MPA, is the Chief Medical Information Officer at Doctors Hospital at Renaissance. Dr. Meza's undergraduate degree is from UT Austin and his MD is from the University of Texas Medical Branch. He also has a Masters of Public Policy and Administration from Columbia University. He holds a clinical appointment at the UTHSCSA-Regional Academic Health Science Center and adjunct appointments at Weill Medical College of Cornell University and at the Department of Health Policy and Management at Texas A&M's School of Rural Public Health. He completed fellowship training in Geriatric medicine and residency in internal medicine at Cornell's New York Presbyterian Hospital.

Jennifer Ellen Miller, PhD (cand.)

Founder & Executive Director, Bioethics International

Jennifer Miller is the Executive Director of Bioethics International (BEI) and its initiative, the World Council for Ethical Standards in Healthcare (WCES), which she founded in 2005. A physicist and bioethicist by training, Miller has interests in the ethics of biomedical research and development (R&D), interactions between pharmaceutical companies and healthcare providers, the publishing and communication of clinical trial data, access to care, and disaster preparedness. Ms. Miller received a BS in Physics from Fordham University in New York, a Licentiate in Bioethics (EU Masters), and is a Doctoral candidate in Bioethics at Regina Apostolorum in Italy.

Maneesha Mithal, JD

Associate Director, Division of Privacy and Identity Protection, Federal Trade Commission, Bureau of Consumer Protection

Maneesha Mithal, JD is the Associate Director of the Federal Trade Commission's Division of Privacy and Identity Protection. In this capacity, she supervises work in the area of data security, identity theft, credit reporting, behavioral advertising, and general privacy. She has held numerous positions at the Federal Trade Commission, including Chief of Staff of the Bureau of Consumer Protection and Assistant Director of the International Division of Consumer Protection.

Pablo Molina

Associate Vice President of Information Technology & Campus Chief Information Officer, Georgetown University

Pablo Molina has been Associate Vice President for Information Technology since 2007 and Campus Chief Information Officer since 2000 at Georgetown University. He regularly speaks at conferences on technology in law and higher education, such as Computer Assisted Legal Instruction, American Bar Association, etc. Pablo serves on national higher education committees and served recently as chair of the EDUCAUSE's Evolving Technologies Committee.

Scott Monteith, MD

Physician & Medical Informaticist, Michigan State University

Dr. Scott Monteith is a graduate of the University of Michigan and Michigan State University. He was chief resident in his psychiatric residency, is board-certified in psychiatry, and a Fellow of the American Psychiatric Association. He is a Clinical Assistant Professor in the departments of Psychiatry and Family Medicine at Michigan State University, has worked with his local community mental health center for nearly 20 years, and is a founder of Behavioral Medicine Associates, PLLC.

Steven W. Mosher

President, Population Research Institute

Steven W. Mosher is the President of the Virginia-based Population Research Institute (1995 to present). He previously served as the Director of the Asian Studies Center at the Claremont Institute from 1986-95. In 1991 he was appointed to serve as Commissioner of the U.S. Commission on Broadcasting to the PRC (1991-2).

Jon A. Neiditz, JD

President, Nelson Mullins Riley & Scarborough

Jon Neiditz is a partner in Nelson Mullins Riley & Scarborough's Atlanta office and founder and co-leader of the Firm's rapidly growing Information Management Practice. Mr. Neiditz is known nationally for developing and implementing cost-effective information governance and management programs that effectively address the risks, costs, and opportunities associated with electronic information. Mr. Neiditz also serves as Chair of the Board of the Georgia Charitable Care Network.

Frank Pasquale, JD

*Schering-Plough Professor in Health Care Regulation and Enforcement, Seton Hall Law School
Affiliate Fellow, Yale Law School's Information Society Project*

Along with his current roles at Seton Hall Law School and Yale Law School, Mr. Pasquale was the Chair of the American Association of Law Schools' Section on Privacy and Defamation in 2011. He has been a visiting professor at Yale and Cardozo Law Schools, and a visiting fellow at Princeton's Center for Information Technology Policy. Pasquale has testified before Congress (appearing with the General Counsels of Google and Microsoft), and has twice presented to committees at the National Academy of Sciences on surveillance technologies. He received a JD from Yale Law School, a M. Phil from Oxford University, and a BA summa cum laude from Harvard University.

2nd International Summit on the Future of Health Privacy

Deborah C. Peel, MD

Founder & Chair, Patient Privacy Rights

Dr. Peel has been a practicing physician and psychoanalyst for over thirty years. In 2004, she formed Patient Privacy Rights (PPR), which has become the nation's and the world's leading consumer health privacy advocacy organization. PPR has over 12,000 members in all 50 states, and leads the bi-partisan Coalition for Patient Privacy, representing over 10.3 million Americans. In 2011, she conceived the idea of the 1st International Summit on the Future of Health Privacy, partnering with the University of Texas LBJ School of Public Affairs and many others to make it a reality.

Joy Pritts, JD

Chief Privacy Officer, Office of the National Coordinator for Health IT, Department of Health and Human Services

Joy Pritts joined the Office of the National Coordinator for Health Information Technology (ONC) in February 2010 as Chief Privacy Officer. Ms. Pritts provides critical advice to the Secretary and the National Coordinator in developing and implementing ONC's HITECH privacy and security programs. She works closely with the Office for Civil Rights and other operating divisions of HHS, as well as with other government agencies to help ensure a coordinated approach to key privacy and security issues.

James C. Pyles, JD

Co-Founder & Principal, Powers, Pyles, Sutter, & Verville

Jim Pyles is a co-founder of Powers, Pyles, Sutter, & Verville and has nearly 40 years of experience in litigation, counseling, and lobbying in the field of health law. Mr. Pyles has more than 20 years of experience in the law of health information privacy at all levels of the federal judiciary, both houses of Congress, and with the Executive branch of the government. Mr. Pyles has testified on numerous occasions before Congress, appeared in court as an expert witness, and made numerous appearances on national television.

Laura Lyman Rodriguez, PhD

Director of the Office of Policy, Communications, and Education, National Human Genome Research Institute, National Institutes of Health (NIH)

Dr. Rodriguez works to develop and implement policy for research initiatives at the NHGRI, as well as trans-NIH programs. She is particularly interested in the policy and ethics questions related to the inclusion of human research participants in genomics and genetics research. Dr. Rodriguez has provided leadership for many of the policy development activities pertaining to genomic data sharing and the creation of the database for Genotypes and Phenotypes (dbGaP) at the NIH.

Marc Rotenberg, JD

Executive Director, Electronic Privacy Information Center (EPIC)

Marc Rotenberg is Executive Director of the Electronic Privacy Information Center (EPIC) in Washington, DC. He teaches information privacy law at Georgetown University Law Center and currently chairs the ABA Committee on Privacy and Information Protection. He is the former Chair of the Public Interest Registry, which manages the .ORG domain. He is editor of *Privacy and Human Rights* and *The Privacy Law Sourcebook*, and co-editor (with Daniel J. Solove and Paul Schwartz) of *Information Privacy Law* (Aspen Publishing 2007).

Mark Rothstein, JD

Herbert F. Boehl Chair of Law & Medicine, Founding Director, Institute for Bioethics, Health Policy and Law, University of Louisville School of Medicine

Mark A. Rothstein holds the Herbert F. Boehl Chair of Law and Medicine and is the Founding Director of the Institute for Bioethics, Health Policy and Law at the University of Louisville School of Medicine. Professor Rothstein has concentrated his research on bioethics, genetics, health privacy, public health law, and employment law. He is the author or editor of 19 books and nearly 200 book chapters and articles in leading journals. His latest book is *Employment Law* (with Craver, Schroeder, & Shoben)(Thomson/West, 4th ed., 2009).

John Sabo, CISSP

Director, Global Government Relations, CA Technologies

John Sabo is the Director of Global Government Relations, CA Technologies, where he focuses on trusted infrastructure technologies, policies, and practices. He provides leadership in industry and government-led data security, privacy, and critical infrastructure protection initiatives and is active in standards development. Mr. Sabo also co-chairs the OASIS Privacy Management Reference Model Technical Committee and serves as chair of the IDtrust Member Section Steering Committee, as well as an OASIS representative to the Internet Technical Advisory Committee for the Organization for Economic Co-operation and Development (OECD).

William M. Sage, MD, JD

Vice Provost for Health Affairs and Law Professor, The University of Texas at Austin

William M. Sage, MD, JD, an authority on health law and policy, is Vice Provost for Health Affairs and James R. Dougherty Chair for Faculty Excellence at the University of Texas at Austin. Professor Sage is a member of the Institute of Medicine of the National Academies, serves on the Fellows Council of the Hastings Center on bioethics, and serves on the editorial board of *Health Affairs*.

COL John S. Scott, MD

Program Director, Clinical Informatics and Accession Medical Policy, Office of the Assistant Secretary of Defense for Health Affairs

COL Scott is a pediatric cardiologist with 22 years of experience in Army medicine. Recognized in his residency as an "early adopter" of health information technology systems, he helped lead user groups to implement new components of the military's electronic medical record systems in various clinical assignments, including two tours to Iraq (2003 and 2009-10). As the Chief of the newly formed Quality Management Division Walter Reed Army Medical Center in 2006, he learned to leverage electronic record systems to help improve and measure clinical quality. In 2010 Scott was designated the Chief Medical Information Officer of Walter Reed and the Joint Task Force, Capital Medicine, leading informatics efforts to support Walter Reed's merger with the National Naval Medical Center to form the Walter Reed National Military Medical Center in 2011. COL Scott was assigned to the Office of the Deputy Assistant Secretary of Defense for Clinical and Program Policy, Health Affairs, in January 2012. He currently serves as the Program Director for Clinical Informatics and Accession Medical Policy, and is part of the team defining the clinical requirements for the Interagency Electronic Health Record, being jointly created by the Department of Defense and the Department of Veterans Affairs.

Kathryn Serkes

Chair & Co-Founder, Doctor Patient Medical Association

Kathryn Serkes is Chair and Co-Founder of the Doctor Patient Medical Association (DPMA) and the Patient Power Alliance, the first national group of patients AND doctors working for freedom in medicine, which was prompted by grassroots activism during the debate on healthcare reform in 2009-2010. She was one of the chief strategists organizing the efforts against socialized medicine legislation, speaking at more than 35 rallies and town halls, and appearing on numerous radio and television shows.

David Staggs, JD

Chief Technology Officer, Jericho Systems Corporation

Chief Technology Officer (CTO) David Staggs is a computer engineer and patent attorney with 30 years of experience in engineering information systems, defining business requirements, leading teams, and developing security standards. Prior to joining Jericho, Staggs managed a team supporting the Nationwide Health Information Network (NwHIN) / Virtual Lifetime Electronic Record (VLER) project sponsored by the Veterans Health Administration (VHA) within the Department of Veterans Affairs (VA).

Michael Stearns, MD

President & CEO, e-MDs

Dr. Stearns is the President and CEO of e-MDs, Inc., a leading national vendor of electronic health records. He is a board certified neurologist who won several teaching awards during his 15 years in clinical and academic medicine. He has 14 years of experience in health information technology and has provided leadership to several high profile projects at the National Library of Medicine, the National Cancer Institute, and the College of American Pathologists.

2nd International Summit on the Future of Health Privacy Is There an American Health Privacy Crisis?

Steve Steffensen, MD

Chief Medical Information Officer, Telemedicine & Advanced Technology Research Center

Dr. Steffensen is a board certified Neurologist and former active duty Navy officer who is recognized as a national leader in healthcare informatics. He has been involved in numerous health IT projects related to the Armed Forces Health Longitudinal Tracking Application (AHLTA) and continues to make significant contributions to the open source health IT community in areas of clinical decision support, data visualization, medical device interoperability, and mobile health solutions.

Nicholas P. Terry, JD

Hall Render Professor of Law, Co-Director of the Hall Center for Law and Health, Indiana University McKinney School of Law

Nicholas P. Terry is the Hall Render Professor of Law at the Indiana University Robert H. McKinney School of Law. He serves as Co-Director of the Hall Center for Law and Health. From 2000 to 2008 Professor Terry served as Co-director of Saint Louis University's Center for Health Law Studies and from 2008 to 2010 as the School of Law's Senior Associate Dean.

Richard Thoreson, PhD

Public Health Advisor, Center for Substance Abuse Treatment, SAMHSA

Richard Thoreson, PhD, public health analyst at SAMHSA since 1992, manages development of open source software for behavioral health and related safety net agencies. For the last 7 years, he has been co-chair of the Community Based Collaborative Care Work Group at Health Level 7, a U.S.-based international standards development organization. HL7 HIT standards underlay many "Meaningful Use" requirements for Electronic Health Records (EHRs) in the U.S. The Workgroup publishes privacy and record content standards specific to specialty behavioral health. The latter are currently in use by the Office of the National Coordinator's Data Segmentation for Privacy Initiative.

Lee Tien, JD

Senior Staff Attorney, Electronic Frontier Foundation

Lee Tien is a Senior Staff Attorney with the Electronic Frontier Foundation (EFF), specializing in free speech law and privacy law, including computer security issues. As a part of his policy work in electronic health records, he advises the California Health and Human Services Agency and its Office of Health Information Integrity as a member of the California Privacy and Security Advisory Board Privacy Steering Team.

Dave Wanser, PhD

Senior Critical Consultant for Intellica

Dave Wanser, PhD, is a Senior Clinical Consultant for Intellica, a health information technology company with a public sector focus and a consultant with a private practice focusing on behavioral health and healthcare technology. He was previously a Visiting Fellow at the Lyndon B. Johnson School of Public Affairs at the University of Texas at Austin from 2007-2011, and a lecturer in the Health Information Technology Program within the College of Natural Sciences.

CAPT Michael Weiner, DO

Chief Medical Officer, Defense Systems

CAPT Michael Weiner is the Acting Deputy Program Manager and Chief Medical officer for the Defense Health Information Management System (DHIMS). As an advocate for the military's medical community, CAPT Weiner advises DHIMS senior leadership and drives delivery of usable solutions to equip health care providers with technology that supports the usability and quality of software applications built to meet the military's clinical needs.

Marcy Wilder

Co-Chair, Global Privacy & Information Management Group, Hogan Lovells US LLP

Marcy Wilder is co-chair of the global Hogan Lovells Privacy and Information Management Group, where her practice focuses on health information law. Ms. Wilder assists clients in managing risks associated with privacy and information practices including compliance with HITECH, HIPAA, and federal and state privacy laws. She also has extensive experience helping clients manage health data breaches. She is recognized as a leading privacy lawyer in both Chambers USA and the Legal 500. Prior to joining Hogan Lovells, she served as Deputy General Counsel of the U.S. Department of Health and Human Services, where she was the lead attorney in the development of HIPAA privacy regulations.



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Clinical Social Work Association



Confederation of Independent Psychoanalytic Societies



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Dialogue on Diversity



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Electronic Frontier Foundation



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