

4<sup>th</sup> International Summit on the Future of Health Privacy



# healthprivacysummit

June 4 – 5, 2014  
Washington, D.C.

Controlling Your Personal Health Information:  
Now Is the Time

**O'NEILL**  
**INSTITUTE**  
FOR NATIONAL & GLOBAL HEALTH LAW  

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GEORGETOWN LAW

patientprivacyrights

[www.healthprivacysummit.org](http://www.healthprivacysummit.org)

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 4<sup>th</sup> International Summit on the Future of Health Privacy.

Now is the time to examine and celebrate privacy as a great necessity in the lives of people across the globe. The health system gathers, stores, and widely disseminates unimaginable amounts of personal information – in health insurance, medical practices, hospitals, and public health agencies. These collections offer a wealth of information that can be used in tremendous ways for the public's good, but without reasonable assurances of privacy, the unauthorized disclosure of health information can be incredibly detrimental to all. This 4<sup>th</sup> International Summit on controlling your personal health information offers us the opportunity to think, research, and act on the need for health information privacy. Georgetown Law and the O'Neill Institute are proud to join with our inspiring partner, Patient Privacy Rights, to host this important conference.



This Summit denotes an essential piece 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 use the law as a positive tool to enable individuals and populations in the United States and throughout the world to lead healthier lives.

We are excited to hear your varied perspectives in the next few days. As always, we hope this summit, with its national and international perspectives on health privacy problems and solutions, will lead to further developments within the field in the coming year.

I would like to thank Deborah Peel and Patient Privacy Rights, as well as our distinguished guests and all of our generous sponsors, for helping to create this outstanding opportunity for ongoing discourse and progress.

Regards,

A handwritten signature in black ink that reads "Larry Gostin". The signature is fluid and cursive.

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,

On behalf of Patient Privacy Rights and the bipartisan Coalition for Patient Privacy, I would like to welcome you to the 4<sup>th</sup> International Summit on the Future of Health Privacy. Together we represent 10.3 million Americans and work to ensure that technology, policy, and laws are designed to restore and maintain individuals' rights to privacy.

The world's attention is now focused on the security and use of sensitive personal data. Senate hearings on the data broker industry, the Target breach, the depth of Edward Snowden's revelations about NSA surveillance, and the White House Office of Science and Technology's Report on Big Data all raise serious questions about government and corporate use of personal data. Now citizens across the globe question whether their data are protected. They want to know when or if individuals can exercise the right of privacy; the right to be "let alone" in the Digital Age.

The 2014 summit title, "Controlling Your Personal Health Information: Now is the Time," reflects the urgency people feel about knowing who holds their most sensitive data – who uses it, and why? In healthcare, the critical need to build in patient access and control over the use of health information is obvious. Although Willis Ware and the US government developed Fair Information Practices (FIPs) in 1974 to protect personal data, US technology systems evolved rapidly without regard to FIPs. Today, hidden surveillance activities and use of health data is the norm in the US.

Our summits are designed to raise public awareness of reality. People need to know when their health data are used and understand the serious deficiencies in data privacy and security protections. A theme this year is the need for two key privacy-enhancing technologies: 1) strong voluntary patient-controlled cyber-IDs to enable direct, secure email with physicians and 2) real-time, automatic electronic access to our own health data (Blue Button Plus).

The summits are unique in including national and international privacy experts. We include leading speakers from civil society organizations, academia, industry, and government. Especially this year, our key international speakers will deeply enhance discussions of top technology and policy issues, as the EU has worked on data privacy and security protections for a much longer time than the US.

It's a great privilege for us to welcome Peter Schaar, Chairman of the European Academy for Freedom of Information and Data Protection (EAID) in Germany, as a keynote speaker. We are also excited to be joined by famed bioethicist Anita Allen, Vice Provost for Faculty at the University of Pennsylvania Law School; Karen DeSalvo, MD, National Coordinator for Health IT; Jeremy Grant, Senior Executive Advisor for Identity Management at NIST; and Adam Tanner, fellow at Harvard University's Institute for Quantitative Social Science.

Once again, the Celebration of Privacy will be a true highlight. We hope you will join us as we honor Peter Schaar and Professor Latanya Sweeney of Harvard with Patient Privacy Rights' 2014 Louis D. Brandeis Privacy Awards.

We would like to extend our special thanks to our remarkable co-host, the O'Neill Institute for National and Global Health Law, for their continued support and dedication to identifying solutions to pressing health privacy concerns. We would also like to thank our amazing academic and industry partners and sponsors, whose generous support makes this event possible. Additionally, we want to thank our international guests, government experts, members of the bipartisan Coalition for Patient Privacy, and the public. Your help enables us to hold this unique-in-the-world forum to examine urgent health privacy issues and solutions.

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

patientprivacyrights

The 4<sup>th</sup> International Summit on the Future of Health Privacy

# *The Celebration of Privacy*

June 4, 2014

6:00 – 8:00 pm

Hyatt Regency Washington on Capitol Hill  
400 New Jersey Ave, NW



*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

Please join us at The Celebration of Privacy for Summit attendees and guests, where we will honor the recipients of the 2014 Louis D. Brandeis Privacy Awards.

The Louis. D. Brandeis Privacy Awardees are 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.

## 2014 Louis D. Brandeis Privacy Awardees



**Latanya Sweeney**

Chief Technology Officer, Federal Trade Commission



**Peter Schaar**

Chairman, European Academy for Freedom of Information and Data Protection

## AGENDA

### DAY 1: WEDNESDAY, JUNE 4, 2014

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

8:00–8:30 am	<b>Registration   Light Breakfast &amp; Coffee</b> <ul style="list-style-type: none"><li>• Sponsored by Park Legal LLC</li></ul>
8:30–9:00 am	<b>Opening Session</b> <ul style="list-style-type: none"><li>• Lawrence O. Gostin, JD   O’Neill Institute for National &amp; Global Health Law</li><li>• Deborah C. Peel, MD   Patient Privacy Rights</li><li>• Shahid Shah, Master of Ceremonies   Netspective Communications</li></ul>
9:00–9:45 am	<b>Keynote: “An Ethical Duty to Protect Your Own Health Privacy”</b> <p>Anita Allen, JD   Vice Provost for Faculty &amp; Professor of Law, University of Pennsylvania Law School</p>
9:50–10:50 am	<b>Privacy, Big Data, &amp; Mobile: Technologies Operating Outside HIPAA Protection</b> <p><i>Moderator:</i></p> <ul style="list-style-type: none"><li>• Nicolas Terry, JD   Indiana University McKinney School of Law</li></ul> <p><i>Panelists:</i></p> <ul style="list-style-type: none"><li>• Andrea M. Matwyshyn, JD   The Wharton School of the University of Pennsylvania</li><li>• Kirk J. Nahra, JD   Wiley Rein LLP</li><li>• Frank Pasquale, JD   University of Maryland Carey School of Law</li><li>• Kathryn Serkes   Doctor Patient Medical Association</li></ul>
10:50–11:10 am	<b>Break</b>
11:10–11:55 am	<b>Keynote: “Privacy In Times of Big Data”</b> <ul style="list-style-type: none"><li>• Peter Schaar   Chairman, European Academy for Freedom of Information and Data Protection (EAID), Germany</li></ul>
12:00–1:00 pm	<b>Lunch</b>
1:00–1:55 pm	<b>Protecting Health Information in Research, Mental Health, and Genetics</b> <p><i>Moderator:</i></p> <ul style="list-style-type: none"><li>• Mark Rothstein, JD   University of Louisville School of Medicine</li></ul> <p><i>Panelists:</i></p> <ul style="list-style-type: none"><li>• Deven McGraw, JD   Manatt, Phelps &amp; Phillips, LLP</li><li>• J.J. Nietfield, MD   University Medical Center Utrecht</li><li>• Alison Rein   Academy Health</li><li>• Sonia Suter, JD   George Washington University Law School</li></ul>
2:00–2:45 pm	<b>Keynote: “A Conversation with Jeremy Grant”</b> <ul style="list-style-type: none"><li>• Jeremy Grant   Senior Executive Advisor for Identity Management, National Institute of Standards and Technology</li><li>• Latanya Sweeney, PhD   Chief Technology Officer, Federal Trade Commission</li></ul>
2:45–2:55 pm	<b>Break</b>

## Controlling Your Personal Health Information: Now Is the Time

2:55–3:50 pm

### Breakout Sessions

#### 1a – Healthcare Laws – U.S. State and International Perspectives

##### Moderator:

- Debra Diener, JD | Privacy and Identity Management Consultant

##### Panelists:

- Ranieri Guerra, MD | Embassy of Italy
- G.S. Hans, JD | Center for Democracy and Technology
- Joanne McNabb, CISSP | California Department of Justice, Office of the Attorney General

#### 1b – Privacy and the New Health Care Models: Real World Problems

##### Moderator:

- Cliff Baker | Meditology Services

##### Panelists:

- Leo Dittimore, HCISPP | Healthcare Partners
- Omar Khawaja, CCSK, CISSP | Highmark

#### 1c – Health Data Exchange – What Is It And What Should You Do? Opt-In or Opt-Out?

##### Moderator:

- Corinne Carey, JD | NYCLU

##### Panelists:

- Mark Jacobs, MHA | Delaware Health Information Network
- John “Mike” Davis | VHA
- Helen Oscislowski, JD | Oscislowski LLC

3:50–3:55 pm

### Break

3:55–4:50 pm

### Do You Know Where Your Health Data Is?

##### Moderator:

- David Staggs, JD | Jericho Systems

##### Speakers:

- Tim Andrews | Booz Allen Hamilton
- Damon Davis, MBA | Office of the National Coordinator for Health IT, HHS
- Shaun Grannis, MD | Indiana University School of Medicine
- Mariann Yeager | Healthway

4:55–5:40 pm

### Keynote: “A Conversation with Karen DeSalvo”

- Dr. Karen DeSalvo, MD, MPH, MSc | National Coordinator for Health Information Technology | US Department of Health & Human Services
- Shahid Shah | CEO, Netspective Communications

5:40–5:45 pm

### Day 1 Closing Remarks

Deborah C. Peel, MD | Founder and Chair, Patient Privacy Rights

*Please proceed to the Hyatt Regency Washington for the Celebration of Privacy*

6:00–8:00 pm

### Celebration of Privacy

## AGENDA

### DAY 2: THURSDAY, JUNE 5, 2014

8:30–9:00 am	<b>Light Breakfast &amp; Coffee</b>
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- Sponsored by IMS Health

9:00–9:05 am	<b>Welcome, Day 2</b>
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- Deborah C. Peel, MD | Founder and Chair, Patient Privacy Rights

9:05–9:50 am	<b>Debate: That Individuals Should Maintain Their Own Health Data</b>
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*A Debate Between Kimberly Gray, Chief Privacy Officer, Global, IMS Health, and Michelle DeMooy, Senior Associate for National Priorities, Consumer Action.*

Many individuals, health reformers, and privacy advocates believe that individuals should maintain their own health data. But, others in the health establishment say that it just won't work; that most people aren't interested enough, or can't manage their data, or will end up holding back research. Listen as Kimberly Gray and Michelle DeMooy debate the merits of each point.

*Moderator:*

- Andy Oram | O'Reilly Media

9:55–10:45 am	<b>Surveillance of Healthcare Data: Who's Looking? What Data Are They Using? What Happened To Fair Information Practices?</b>
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*Moderator:*

- Deborah Hurley, JD | Hurley

*Speakers:*

- Kaliya Hamlin | Personal Data Ecosystem Consortium
- Paul Hattis, JD, MD | Tufts University Medical School
- Nathan Wessler, JD | ACLU

10:45–11:00 am	<b>Break</b>
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11:00 am–12:00 pm	<b>Assuring An Individual's Access to Her Own Health Records</b>
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*Moderator:*

- Peter Levin, PhD | Center for a New American Security

*Speakers:*

- Joan Antokol, JD | Park Legal LLC
- Adrian Gropper, MD | Patient Privacy Rights
- Joy Pritts, JD | Office of the National Coordinator for Health IT, HHS
- Ron Walters, MD | MD Anderson

*Please proceed to the Hyatt Regency Washington for the seated Luncheon Keynote*

12:15–1:25 pm	<b>Luncheon Keynote: "The Search for the Mystery Woman and Other Naked Truths Learned from Re-Identification"</b>
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- Adam Tanner | Fellow, Harvard University's Institute for Quantitative Social Science

1:25–1:30 pm	<b>Summit Closing Remarks</b>
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- Deborah C. Peel, MD | Founder and Chair, Patient Privacy Rights

## FEATURED SPEAKERS



**Anita Allen, JD**

Vice Provost for Faculty  
University of Pennsylvania

Anita L. Allen is an expert on privacy law, bioethics, and contemporary values, and is recognized for her scholarship about legal philosophy, women's rights, and race relations. In 2013, Allen was appointed the University of Pennsylvania's Vice Provost for Faculty. In 2010 she was appointed by President Obama to the Presidential Commission for the Study of Bioethical Issues. Her books include *Unpopular Privacy: What Must We Hide* (Oxford, 2011); *Everyday Ethics: Opinion-Writing about the Things that Matter Most* (Academic Readers/Cognella, 2010); *Privacy Law and Society* (Thomson/West, 2011); *The New Ethics: A Guided Tour of the 21st Century Moral Landscape* (Miramax/Hyperion, 2004); *Why Privacy Isn't Everything: Feminist Reflections on Personal Accountability* (Rowman and Littlefield, 2003); and *Uneasy Access: Privacy for Women in a Free Society* (Rowman and Littlefield, 1988).

She co-edited (with Milton Regan) *Debating Democracy's Discontent* (Oxford, 1998). Allen, who has written more than a 100 scholarly articles, has also contributed to popular magazines and blogs, and has frequently appeared on nationally broadcast television and radio programs. Allen has served on numerous editorial and advisory boards, and on the boards of a number of local and national non-profits and professional associations including the Hastings Center, EPIC, and the Bazelon Center.

**Karen DeSalvo, MD, MPH, MSc**

National Coordinator for Health Information Technology  
U.S. Department of Health and Human Services

Dr. Karen DeSalvo is a physician who has focused her 20-year career toward improving access to affordable, high quality care for all people with a focus on vulnerable populations and to improving overall health. She has done this through direct patient care, medical education, policy and administrative roles and as a researcher. As the National Coordinator for Health Information Technology, she is leading the nation's charge to promote, adopt, and meaningfully use health information technology in order to achieve better care, and lower costs in health care and improve the overall health of everyone in America.



Before joining the U.S. Department of Health and Human Services, she was Health Commissioner for the City of New Orleans, and New Orleans Mayor Mitchell Landrieu's Senior Health Policy Advisor.

While there, she transformed the outmoded health department in to a modern and effective one, and restored health care to devastated areas of the city, including leading the establishment of a public hospital. Prior to joining the Mayor's administration, Dr. DeSalvo was a professor of medicine and vice dean for community affairs and health policy at Tulane University School of Medicine.

She earned her Medical Doctorate and Master's in Public Health from Tulane University, and Master's in Clinical Epidemiology from Harvard School of Public Health. She has an honorary doctorate from her alumnus institution, Suffolk University.



## FEATURED SPEAKERS



### **Jeremy Grant**

Senior Executive Advisor for Identity Management  
National Institute of Standards and Technology

Jeremy Grant is the Senior Executive Advisor for Identity Management at the National Institute of Standards and Technology (NIST). Grant joined NIST in February, 2011 to lead the establishment of a National Program Office to implement the National Strategy for Trusted Identities in Cyberspace (NSTIC). He comes to NIST with a diverse background and deep understanding of identity and cyber security issues, having served in a range of leadership positions spanning government, technology firms and the financial services sector. He is a former co-chair of the Identity Management Committee at TechAmerica. He is a graduate of the University of Michigan.

### **Peter Schaar**

Chairman of the European Academy for Freedom of Information and Data Protection (EAID); former German Federal Commissioner for Data Protection and Freedom of Information

Mr. Schaar was born in Berlin in 1954 and has a degree in Economics. From 1980 to 1986 he worked in various functions in the city administration of Hamburg. From 1986 to 2002 he was employed in the office of Hamburg's Data Protection Commissioner, initially as the head of the technology unit and later as deputy commissioner. From 2002 to 2003 he was the founder and managing director of a consulting company for data protection. From 2003 to 2013 he was the Federal Commissioner for Data Protection and Freedom of Information. He also currently works as lecturer at the University of Hamburg. In 2013 he was elected as chairman of the European Academy for Freedom of Information and Data Protection.

Awards: Prize of the Friedrich-Ebert-Foundation "Das politische Buch 2008" ("The Political Book 2008") for the book *Das Ende der Privatsphäre* (The End of Privacy); "eco Internet AWARD 2008", the special award of the Association of the German Internet Industry; Data Protection Award of the German Association for Data Protection and Data Security (GDD) 2013



## FEATURED SPEAKERS



### **Adam Tanner**

Fellow

Harvard's Institute for Quantitative Social Science

Adam Tanner is a fellow at Harvard's Institute for Quantitative Social Science. He has been at Harvard since the 2011-12 academic year when he was a Nieman fellow. He recently completed "What Stays in Vegas: The World of Personal Data – Lifeblood of Big Business – and the End of Privacy as We Know It," a book to be published Sept. 2nd by Public Affairs (Perseus Group).

From 1995 until 2011, Tanner worked for Reuters, including as bureau chief for the Balkans and in San Francisco. In other postings he served in Germany, Russia and Washington D.C. He was part of the Reuters team cited in 2012 as a Pulitzer finalist in international reporting. He has appeared on the BBC and National Public Radio, and writes for Forbes, Worth and other magazines.

The 2014 winner of the NYU Arthur L. Carter Journalism Institute's Reporting Award, Tanner is now researching the business of medical data. In his latest work, he is looking at the pharmaceutical data/information marketplace and the complex trade in personal medical details generated from doctor visits, hospital stays and other medical treatments. Key questions include what data is widely available, what vulnerabilities and how can system be strengthened for the future. The research will also examine how the availability of such big data helps advance medical science.

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## SUMMIT SPEAKERS

### **Tim Andrews**

*Vice President | Booz Allen Hamilton*

Timothy A. Andrews, a Booz Allen Hamilton Vice President, is a leader of the Health Market Team that provides strategy and organization, analytics, technology, and cyber security services across the payor, provider, and life sciences market segments. Important focus areas include: Health reform, Health IT, data science and health information exchange. Mr. Andrews works with government entities, communities, and provider and payor organizations to implement integrated healthcare platforms aimed at improving safety while reducing cost. He also works with organizations implementing Health Reform, including Patient Centered Medical Homes and Accountable Care Organization. He has an A.B. degree in engineering from Dartmouth College and an MSCS/EE from Worcester Polytechnic Institute.

### **Joan Antokol, JD**

*Managing Partner | Park Legal LLC*

Joan Antokol is the managing partner of Park Legal LLC, an Indianapolis-based law firm that focuses its practice in the areas of data protection, security and records management. She is also the founder of an online training company and a software company. She assists a wide variety of global and local organizations with many aspects of privacy, security, records management and compliance. Her services include assisting companies in developing and implementing their data privacy and security programs, handling security breaches, and assisting companies with Safe Harbor certification and other aspects of data transfer compliance. For the last decade, her work in the privacy and security area has been based on the *Privacy by Design* approach, and she has created the *PbD* framework and implementation measures for a variety of organizations in establishing their privacy and security programs.

## Controlling Your Personal Health Information: Now Is the Time

### **Cliff Baker**

*Managing Partner | Meditology Services*

Cliff Baker is the Managing Partner at Meditology Services. He is an industry leader in healthcare information technology, privacy and security, and has over 17 years of industry experience. Cliff has worked with the nation's leading healthcare organizations across all sectors of the industry and has served as an executive advisor for key industry affiliations and companies. He is a sought after contributor and speaker for various health IT and information risk management forums, the lead author of the HITRUST Common Security Framework, and author of various IT Risk Management publications. Prior to forming Meditology, Cliff was the Chief Strategy Officer for HITRUST and also led PricewaterhouseCoopers' healthcare security practice.

### **Corinne Carey, JD**

*Assistant Legislative Director | NYCLU*

Corinne A. Carey is Assistant Legislative Director of the New York Civil Liberties Union where she has engaged in advocacy around a wide range of civil liberties issues, with particular emphasis on public health and medical privacy. Ms. Carey graduated summa cum laude from SUNY Buffalo School of Law in 1998. She began her legal career with a fellowship from the Open Society Foundation as founder and director of the Harm Reduction Law Project where she represented homeless and marginally-housed clients in New York City on matters relating to privacy, discrimination, and benefits eligibility. Prior to joining the NYCLU, Ms. Carey was a researcher with the U.S. Program at Human Rights Watch. Ms. Carey has been analyzing the privacy implications of New York State's transition to electronic health information exchange since 2007 and is the author of NYCLU's report *Protecting Patient Privacy: Strategies for Regulating Electronic Health Records Exchange*. She serves on the policy committee for the New York State eHealth Collaborative, a body that recommends best policies and procedures for advancing electronic health information exchange and protecting patient privacy.

### **Damon Davis, MBA**

*Special Assistant | Office of the National Coordinator for Health IT, HHS*

Damon Davis serves as Special Assistant in the Office of the National Coordinator for Health IT (ONC) in the U.S. Department of Health & Human Services. He joined the department in 2009. Mr. Davis works in ONC's Office of Consumer eHealth (OCeH) focusing on increasing consumer access to secure electronic personal health information. OCeH promotes greater Access to health information, consumers taking Action with their electronic health data toward better health outcomes, and Attitude changes on the part of providers and patients and families to promote shared decision making in a health IT enabled health care system. His work includes managing the Blue Button Pledge Community, which is comprised of over 400 public, private, and non-profit organizations that have pledged to grant easy secure electronic access to personal health information through Blue Button and promote the use of Health IT to the constituents they serve. Additionally he is responsible for the consumer component of ONC's Investing in Innovation (I2) initiative. Mr. Davis holds a Bachelor of Science degree from Hampton University and a Masters of Business Administration from Loyola College of Maryland.

### **John "Mike" Davis**

*Security Architect | Department of Veterans Affairs*

Mr. Davis is the Security Architect for the Department of Veterans Affairs Veterans Health Administration. He develops innovative security architectures improving clinician access to electronic health records while spearheading privacy enhancing technologies providing US Veterans choice for what and with whom their information may be shared. He leads VHA emerging health technology investigations internally and participates in ONC/FHA projects externally. As Co-Chair of the HL7 Security Working Group, he has led the development of numerous international security standards serving the healthcare community. Recently, Mr. Davis led a VHA team that developed pilot implementations, demonstrations under ONC initiatives, and successfully balloted the HL7 Data Segmentation for Privacy Implementation Guide. He also developed the first ever international healthcare standard capable of classifying privacy sensitive content. Mr. Davis has co-authored several security books and various articles in Healthcare Informatics Journals.

### **Michelle DeMooy**

*Senior Associate, National Priorities | Consumer Action*

Michelle DeMooy is Senior Associate, National Priorities with Consumer Action. She is the lead advocate for digital privacy rights, focusing on online privacy, health privacy, identity, biometrics, Do Not Track, app privacy, and the overall impact of privacy issues on underserved and disadvantaged communities. Michelle creates and advocates for pro-consumer policy, regulation, and legislation by facilitating dialogue between industry and other stakeholders to build practical and innovative solutions to privacy questions. Michelle currently sits on the Advisory Board of the Future of Privacy Forum, a privacy think tank located in Washington, D.C. and has been a panelist and featured speaker at many events related to digital privacy, including Federal Trade Commission workshops, the Internet Governance Forum, Health Privacy Summit, and State of the Mobile net. Prior to Consumer Action, Michelle was a Senior Consultant for eCampaigns at M+R Strategic Services and a senior marketing manager for Investor Broadcast Network. She was also involved in the early days of the first dotcom boom, developing software and website projects for startups in San Francisco, including Looksmart, Ltd. Michelle graduated from Lehigh University in 1997 with a degree in Government.

### **Debra N. Diener, JD, CIPP/G**

*Privacy and Identity Management Consultant*

Debra N. Diener's career has spanned over 30 years, including senior managerial, legal, policy and legislative positions in all three branches of the Federal Government. Her last federal position was as the Senior Advisor and Director of Privacy Policy for the Department of Homeland Security. She is now an independent consultant providing strategic guidance to corporate and non-profit organizations for which she helps craft and implement privacy enhancing business solutions. She also writes a consumer-oriented privacy blog ([www.PrivacyMadeSimple.net](http://www.PrivacyMadeSimple.net)). In addition to her consulting and blogging, Debra also contributes her time as a member of the Open Identity (OIX) Advisory Board, the Shared Assessments Advisory Board and the Patient Privacy Rights Board. Debra received her B.A. *cum laude* from Syracuse University, her M.A. from the University of Pennsylvania, and her J.D. *with honors* from the George Washington University. She is also a Certified Information Privacy Professional with a Government specialization.

### **Leo Dittmore, HCISPP**

*Director, Information Privacy & Security | HealthCare Partners*

Leo is currently the Director Information Services Privacy & Security at HealthCare Partners. He is an executive with extensive project management, consulting, and operations experience. He provides leadership and technical expertise in implementation and operations management of distributed systems, applications, and deployments. He has extensive experience in secure operations, systems design, systems management, and network systems support. His experience includes the design, deployment, and support of electronic medical records, e-business systems, Internet/Intranet applications, electronic mail, office automation, and desktop applications. Leo has a Bachelor of Science in Computer Science magna cum laude from West Coast University and has done Graduate studies at Carnegie-Mellon University's Information Networking Institute. He recently helped design the criteria and test for the Healthcare Information Security and Privacy Practitioner (HCISPP) certification that he now holds.

### **Lawrence Gostin, JD**

*University Professor | Georgetown University*

Lawrence Gostin is University Professor and the Founding Linda and Timothy O'Neill Chair in Global Health Law; Faculty Director of the O'Neill Institute for National and Global Health Law; and Director of the WHO Collaborating Center on Public Health Law & Human Rights. He has chaired numerous National Academy of Sciences committees; proposed a Framework Convention on Global Health endorsed by the UN Secretary General; served on the WHO Director's Advisory Committee on Reforming the WHO; drafted a Model Public Health Law for WHO and the CDC; and directed the National Council of Civil Liberties and the National Association for Mental Health in the United Kingdom, where he wrote the British Mental Health Act and brought landmark cases before the European Court of Human Rights. He was awarded the Delbridge Memorial Prize for the person who has "most influenced Parliament and government to act for the welfare of society."

## Controlling Your Personal Health Information: Now Is the Time

### **Shaun Grannis, MD, MS, FAFAP**

*Assistant Professor of Family Medicine | Indiana University School of Medicine*

After receiving an Aerospace Engineering degree from MIT and undergoing post-doctoral training in Medical Informatics and Clinical Research at Regenstrief Institute and Indiana University School of Medicine, Dr. Grannis joined Indiana University in 2001. He has developed close collaborations with national and international public health stakeholders to advance technical infrastructure, data-sharing, and patient matching capabilities. He is a member of World Health Organization Collaborating Center for the Design, Application, and Research of Medical Information Systems, where he addresses issues related to health information system identity management and patient matching; implementing automated patient matching strategies; and collaborating with WHO on the design, development, and implementation of enterprise medical record system architectures. Dr. Grannis has also developed methods to improve the accuracy and efficiency of patient matching. He developed patient matching methods that have informed national record linkage policy and has been an invited expert for CDC advisory panels working to identify best practices for patient identification.

### **Kimberly Gray, JD**

*Global Chief Privacy Officer | IMS Health*

Kimberly S. Gray is global chief privacy officer of IMS Health, the world's leading provider of market intelligence to the pharmaceutical and healthcare industries. She is responsible for the development, oversight and promotion of IMS Health's comprehensive privacy, data protection and data management program, which includes policy development, communications and strategic direction for the company. She has served as an adjunct professor at the Dickinson School of Law of the Pennsylvania State University and in the master's program of Shippensburg University. Gray serves on the Future of Privacy Forum, the Ponemon Institute's RIM Council, the Centre for Information Policy Leadership (CIPL), the Ethics Committee of the European Pharmaceutical Market Research Association (EphMRA), the Confidentiality Coalition of the Healthcare Leadership Council and the Executive Council of HITRUST. She holds a Juris Doctor from The Dickinson School of Law of the Pennsylvania State University. She lectures frequently on privacy and information security issues.

### **Adrian Gropper, MD**

*Chief Technology Officer | Patient Privacy Rights*

Dr. Gropper is a pioneer in patient-centered and patient-controlled health records on the Internet. He holds an engineering degree from MIT and an MD from Harvard Medical School. Work on telemedicine and picture archiving and communications systems (PACS) with Massachusetts General Hospital introduced him to MIT's Guardian Angel project, the parent of many of today's patient-facing technologies. In 1995, Dr. Gropper founded AMICAS as the first Web-based radiology PACS. He also founded MedCommons and has participated in many early standardization efforts including IHE, HITSP, and Liberty Alliance. He serves on the Massachusetts HIE Technology Workgroup, the Massachusetts Medical Society Committee for IT, and Markle Foundation panels. He also participates as a patient-access advocate in the NwHIN Direct Project, BB+ health information exchange, and the NSTIC/IDESG cyber ID initiative. His focus is technology that applies fair information practice to our new world of continuous surveillance and predictive analytics.

### **Ranieri Guerra, MD**

*Scientific Attache | Italian Embassy*

Ranieri Guerra is a physician, specialized in public health in Italy and the UK. He has practiced in several areas of the world, besides Italy, belonging to the small club of visitors to more than 150 countries. His professional interests and experiences range from emergency and rescue operations (especially in war torn areas) to the design and implementation of health reforms in less developed and in transitional countries. Before moving to DC, where he is scientific attaché at the Embassy of Italy, he was research director at the Italian National Institute of Health (where he conducted large trials mainly in telematics and ehealth) and director of health at UNRWA, the UN agency for Palestinian Refugees. He served also in the Technical Review Panel of the Global Fund for AIDS, TB and Malaria and with the EU development aid in several ACP countries.

### **Kaliya Hamlin**

*Founder & Executive Director | Personal Data Ecosystem Consortium*

Kaliya Hamlin is an expert in user-centric identity and data sharing and is widely known as Identity Woman (it's also the name of her blog and twitter handle). She is the co-founder of efemurl: A Community Empowerment Platform. In 2005, she co-founded the Internet Identity Workshop (with Doc Searls and Phil Windley), five years later she founded the Personal Data Ecosystem Consortium to catalyze a network of companies working to give individuals the tools to collect, manage and gain value from their own personal data generated actively and passively as they interact with all kinds of digital systems. She was elected in August 2012 to the National Strategy for Trusted Identities in Cyberspace (NSTIC) Identity Ecosystem Steering Committee, Management Council as the Consumer Advocate delegate. In 2012, Hamlin was named a Young Global Leader by the World Economic Forum (WEF). She sits on the OASIS IDTrust member steering committee and is active in the Federated Social Web, which recently moved its work to the W3C.

### **G.S. Hans, JD**

*Ron Plesser Fellow | Center for Democracy & Technology*

Gautam Hans is CDT's 2012-2014 Ron Plesser Fellow. At CDT, his work focuses on consumer privacy, including mobile technology, government regulation and enforcement, and international issues. He also works on consumer privacy intersections with free expression and national security issues, and the continuing evolution of data collection and use through platforms and devices. Gautam also has written multiple policy papers and administrative comments while at CDT, touching on issues ranging from big data to mobile device tracking to international privacy regulation. In 2006, Gautam earned his B.A. in English and Comparative Literature from Columbia University. In 2012, Gautam earned his J.D., *cum laude*, from the University of Michigan Law School and his M.S. in Information from the University of Michigan School of Information. He is a member of the Maryland bar.

### **Paul Hattis, JD, MD, MPH**

*Senior Associate Director of MPH Program | Tufts University Medical School*

Dr. Hattis has worked in a wide variety of roles in the fields of health administration, law and policy as well as in the field of preventive medicine. Currently, he serves as Senior Associate Director of the MPH Program at Tufts University Medical School and is an Associate Professor in the Department of Public Health and Community Medicine. Dr. Hattis' research efforts have recently focused on the issue of educating consumers on health care costs, where he and Tufts colleagues have joined with a local consumer advocacy organization on a Robert Wood Johnson funded effort to support community engagement. Dr. Hattis was appointed to the groundbreaking Massachusetts Health Policy Commission in 2012. He currently chairs the Community Health Care Investment and Consumer Involvement Committee, and is also a member of the Cost Trends and Market Performance Committee. Dr. Hattis received his medical and law degrees from the University of Illinois, where he was part of the Medical Scholars Program. He also received a Masters of Public Health degree from UCLA and a Bachelor of Science from the University of Michigan. Dr. Hattis is board certified in Public Health and Preventive Medicine and is a Fellow of the American College of Preventive Medicine.

### **Deborah Hurley, JD**

*Principal | Hurley*

Deborah Hurley is the Principal of the consulting firm she founded in 1996, which advises governments, international organizations, companies, civil society organizations, and foundations on advanced science and technology policy. She is a Fellow of the Institute for Quantitative Social Science at Harvard University and directed the Harvard University Information Infrastructure Project. At the Organization for Economic Cooperation and Development (OECD), in Paris, France, she identified emerging legal, economic, social and technological issues related to information and communications technologies, biotechnology, environmental and energy technologies, nanotechnology, and science and technology policy. She is also Chair, Board of Directors, Electronic Privacy Information Center, and the author of *Pole Star: Human Rights in the Information Society*, "Information Policy and Governance" in *Governance in a Globalizing World*, and other publications.

## Controlling Your Personal Health Information: Now Is the Time

### **Mark Jacobs, MHA**

*Chief Information Officer | Delaware Health Information Network*

Mark J. Jacobs, MHA, is the first Chief Information Officer (CIO) for the Delaware Health Information Network (DHIN). Jacobs brings considerable healthcare and information technology experience to the statewide Health Information Exchange. He has amassed more than 30 years of Health Information Technology with several leading health systems. Previous roles include Director of Technology for Wellspan Health System, Director of Technology for Lancaster Health Alliance and Director of Information Technology for Wyoming Valley Health System. Mark holds a Masters Degree in Health Administration from Wilkes University and has attained the status of Certified Professional in Health Information Management Systems (CPHIMS).

### **Omar Khawaja, CCSK, CISSP**

*VP and Chief Information Security Officer | Highmark*

Omar Khawaja has spent 14 years delivering, developing and managing enterprise security solutions. He is currently VP and Chief Information Security Officer at Highmark, the nation's third largest integrated health delivery and financing network. In the past, Khawaja had responsibility for a portfolio of security solutions with customers in 72 countries. Khawaja has advised executives of the Global 1000 and spoken at industry conferences (RSA, CSA, ISF, MWC, WEDI ...) on the topic of making security more business-centric, on 5 continents. Khawaja has been quoted in media outlets such as Financial Times, NY Times and CNBC. Khawaja is a CCSK, CPHIMS and CISSP; has a BS in electrical engineering from Georgia Tech and an MBA from University of Virginia's Darden School of Business.

### **Peter L. Levin, PhD**

*Founder & CEO | Amida Technology Solutions*

Peter L. Levin is the founder and CEO of Amida Technology Solutions, an information technology firm that focuses on health data and data security. From 2009 to 2013, he served as Senior Advisor to the Secretary and Chief Technology Officer of the Department of Veterans Affairs, where he led their health record modernization initiative. In this role, he co-created and led the inter-agency development of the Blue Button personal health record, the creation and implementation of the open source electronic health record custodian, and delivery of the first clinical components of the integrated electronic health record with DoD. Peter studied at Carnegie Mellon University, where he received his BS, MS and PhD in Electrical and Computer Engineering, and was a post-doctoral student and DAAD Visiting Scientist at the Institute for High Voltage Engineering at the Technical University of Munich.

### **Andrea Matwyshyn, JD, PhD**

*Senior Policy Advisor, Office of Policy Planning | Federal Trade Commission*

Andrea M. Matwyshyn joined the FTC's Office of Policy Planning as a Senior Policy Advisor in December of 2013, where she advises the agency on privacy and data security policy issues. Dr. Matwyshyn is also an assistant professor in the Legal Studies and Business Ethics Department in the Wharton School and an affiliate of the Center for Technology, Innovation and Competition at the University of Pennsylvania Law School. She studies technology innovation and its legal implications, particularly corporate information security regulation and consumer privacy. She also serves as a faculty affiliate of the Center for Internet and Society at Stanford Law School. She has a JD, a PhD in human development and social policy, and a master's degree in international relations from Northwestern University.

### **Deven McGraw, JD**

*Partner | Manatt, Phelps & Phillips, LLP*

Deven McGraw is a partner in the healthcare practice of Manatt, Phelps & Phillips, LLP. She provides legal, regulatory and strategic policy and business counsel to healthcare providers, payers and other organizations with respect to the adoption and implementation of health IT and electronic health information exchange. Areas of focus include HIPAA/privacy advice and compliance, data security, data governance, research and health data analytics, health IT policy, and patient engagement. Previously, Ms. McGraw was the Director of the Health Privacy Project at the Center for Democracy & Technology. She also served on several committees established by the U.S. Department of Health and Human Services, providing guidance on a range of health IT, privacy and security issues. Ms. McGraw received an LLM and JD from Georgetown University Law Center, an MPH from Johns Hopkins School of Hygiene and Public Health, and a BS from the University of Maryland.

### **Joanne McNabb, CIPP/US, CIPP/G, CIPP/IT**

*Director of Privacy Education & Policy | California Department of Justice, Office of the Attorney General*

Joanne McNabb is the Director of Privacy Education and Policy in the Privacy Enforcement and Protection Unit in the California Department of Justice. The Unit protects Californians' constitutional right to privacy, enforces state and federal privacy laws, educates consumers and businesses, and makes recommendations to the Attorney General on privacy matters. McNabb is a Certified Information Privacy Professional, with specializations in Government and Information Technology. She serves on the Privacy Advisory Committee to the U.S. Department of Homeland Security and is a Fellow of the Ponemon Institute. From 2001 to 2012, McNabb directed the California Office of Privacy Protection, which was a resource and advocate on privacy issues. She attended Occidental College and holds a master's degree in Medieval Literature from the University of California, Davis.

### **Kirk Nahra, JD**

*Partner | Wiley Rein LLP*

Kirk J. Nahra is a partner with Wiley Rein LLP in Washington, D.C., where he specializes in privacy and information security litigation and counseling, along with a variety of health care and compliance issues. He is chair of the firm's Privacy Practice and co-chair of its Health Care Practice. He assists companies in a wide range of industries in analyzing and implementing the requirements of privacy and security laws across the country and internationally. A long-time member of the Board of Directors of the IAPP, he also served as the editor of Privacy Advisor, the monthly newsletter of the IAPP, for more than a decade. He can be reached at 202.719.7335 or knahra@wileyrein.com. Follow him on Twitter @kirkjnahrawork.

### **J.J. Nietfeld, M.Sci, PhD**

*Associate Professor | University Medical Center, Utrecht*

J.J.Nietfeld received his M.Sci. degree in Mathematics and Natural Sciences and his Ph.D. degree in Biochemistry from the University of Amsterdam. After another specialization at Utrecht University he has been certified as a Pathobiologist. He has been working for over 30 years in universities and university hospitals in the Netherlands and the U.S.A. and was awarded 4 times a fellowship of The Netherlands Organisation for Health Research and Development. He has been a leader, co-organizer and member in several projects/groups to advise the Dutch Government and Parliament on biobanks. Presently, he is associate professor/senior scientist at the University Medical Center in Utrecht and director of INTRESCO, a biotech SME, both in the Netherlands. For biomedical data protection, Dr. Nietfeld has invented the Bio-PIN, a biological PIN code that enables the anonymous storage of patient samples/data while a 2-way anonymous communication between the patient and the keeper of the samples/data is possible.

### **Andy Oram**

*Editor | O'Reilly Media*

Andrew Oram is an editor at O'Reilly Media, a highly respected book publisher and technology information provider, where he specializes in books and articles on free software, networking, health IT, and software engineering. He writes frequently about policy issues related to the Internet and about trends affecting technical innovation and its effects on society. Print publications where his work has appeared include The Economist, Communications of the ACM, the Journal of Information Technology and Politics, Vanguardia Dossier, Copyright World, and Internet Law and Business.

### **Helen Oscislawski, Esq.**

*Founding Partner | Oscislawski LLC*

Helen is a corporate and regulatory attorney whose practice focuses almost exclusively on advising and representing healthcare clients. She is widely recognized for her experience with and understanding of legal issues that arise with electronic medical records and networked health information exchange. In 2008, Governor Corzine appointed Helen to the New Jersey Health Information Technology Commission (NJHITC). In 2010, she was reappointed to the NJHITC by Governor Christie, and was tapped to serve as Chair of the State's Privacy and Security Committee. She has completed complex legal analyses regarding patient consent issues, privacy standards, security breach response, and other HIPAA and privacy challenges. Helen currently advises organizations on all aspects of strategic and legal planning for HIE and maintains the popular blog Legal HIE ([www.legalhie.com](http://www.legalhie.com)).



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### **Frank Pasquale, JD**

*Professor of Law | University of Maryland Carey School of Law*

Frank Pasquale's research agenda focuses on challenges posed to information law by rapidly changing technology, particularly in the health care, internet, and finance industries. He has published over 30 scholarly articles, and his book *The Black Box Society: The Hidden Algorithms Behind Money and Information* will be published by Harvard University Press in Fall, 2014. His article *Grand Bargains for Big Data: The Emerging Law of Health Information* offers a broad overview of the opportunities and perils posed by the growing use of predictive analytics in the medical field. Pasquale graduated *summa cum laude* from Harvard University, received an MPhil at Oxford University as a Marshall Scholar, and received his JD from Yale Law School. He has been a Visiting Fellow at Princeton's Center for Information Technology, a Visiting Professor at Yale Law School and Cardozo Law School, and was a Marshall Scholar at Oxford University. He has testified before the Judiciary Committee of the House of Representatives (appearing with the General Counsels of Google, Microsoft, and Yahoo) and presented before a Department of Health & Human Services/Federal Trade Commission Roundtable and panels of the National Academy of Sciences.

### **Deborah Peel, MD**

*Founder & Chair | Patient Privacy Rights*

Deborah C. Peel, MD is the world's leading advocate for patients' rights to control the use of personal health information in electronic systems. She is also a practicing physician and Freudian psychoanalyst. In 2004, she formed Patient Privacy Rights (PPR), a 501c3 non-profit organization, to educate Americans about the urgent need to restore patient control over health data. PPR is the world's leading advocate for health privacy, with over 20,000 members in all 50 states. In 2006, she founded the bipartisan Coalition for Patient Privacy, which includes over 50 national organizations, representing 10.3 million people who want to control the use of personal health information. Since 2007, Dr. Peel has been included on ModernHealthcare magazine's "100 Most Influential in Healthcare" list four times. In 2013, she was named one of the "Top Ten Influencers in Health InfoSec" by HealthcareInfoSecurity.

### **Joy Pritts, JD**

*Chief Privacy Officer | Office of the National Coordinator for Health IT, HHS*

Joy Pritts joined the Office of the National Coordinator for Health Information Technology (ONC) in 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. Prior to joining ONC, Ms. Pritts was on the faculty at Georgetown University where she held a joint appointment as a Senior Scholar with the O'Neill Institute for National and Global Health Law and as a Research Associate Professor with the Health Policy Institute. Her work has focused on the critical issues surrounding the privacy of health information and patient access to medical records at both the federal and state levels. Ms. Pritts holds a law degree from Case Western Reserve University School of Law, and a Bachelor of Arts degree from Oberlin College.

### **Alison Rein**

*Senior Director for Evidence Generation & Translation | AcademyHealth*

Alison Rein is a Senior Director for Evidence Generation and Translation at AcademyHealth. In this role, she directs several projects that investigate how new sources of data and expanded stakeholder engagement are helping transform health care and research. She is the principal investigator on the PCORI Pilot Projects Learning Network, where she leads a team that actively manages and facilitates collaboration among 50 pilot projects to advance the field of patient centered outcomes research (PCOR). She also co-leads work on behalf of PCORI to develop an action plan for the dissemination and implementation of comparative effectiveness research (CER) findings, as well as the process for evaluating those efforts. Ms. Rein also oversees or contributes to projects that focus on building infrastructure to support quality improvement, comparative effectiveness research, and PCOR. She holds a master's degree in public policy analysis from the University of Rochester.

**Mark Rothstein, JD**

*Herbert F. Boehl Chair of Law & Medicine,*

*Director of the Institute for Bioethics, Health Policy, & Law | University of Louisville School of Medicine*

Mark A. Rothstein is the Herbert F. Boehl Chair of Law and Medicine and Director of the Institute for Bioethics, Health Policy, and Law at the University of Louisville School of Medicine. He has concentrated his research on health privacy, bioethics, genetics, and public health. From 1999-2008, he was a member of the National Committee on Vital and Health Statistics (NCVHS), where he chaired the Subcommittee on Privacy and Confidentiality. He is a past president of the American Society of Law, Medicine and Ethics, a member of the American Law Institute, and a fellow of the Hastings Center. He currently serves as Department Editor for Public Health Ethics and Law of the American Journal of Public Health. Since 2000, he has written a column on bioethics for the Journal of Law, Medicine and Ethics. He is the author or editor of 19 books and over 200 book chapters and articles. He is also a 2013 recipient of the Louis D. Brandeis Privacy Award from Patient Privacy Rights. He received a B.A. from the University of Pittsburgh and a J.D. from Georgetown University.

**Kathryn Serkes**

*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.

**Shahid Shah**

*CEO | Netspective Communications*

Shahid is an internationally recognized enterprise software guru that specializes in healthcare IT with an emphasis on e-health, EHR/EMR, Meaningful Use, data integration, medical device connectivity, health informatics, and legacy modernization. Over the last 15 years, the health IT positions he's held include Chairman of OSEHRA's Advisory Board, CTO for CardinalHealth's CTS unit (now CareFusion), CTO of two Electronic Medical Records (EMR) companies, a Chief Systems Architect at American Red Cross, Architecture Consultant at NIH, and SVP of Healthcare Technology at COMSYS.

**David Staggs, JD, CISSP**

*Chief Technology Officer | Jericho Systems*

David Staggs is a computer architect 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). He holds a J.D. from Thomas Jefferson School of Law, two B.A.s from University of California Santa Cruz, and certification as a Certified Information Systems Security Professional (CISSP). He has authored eight technical standards.

**Sonia Suter, JD**

*Professor of Law | George Washington University*

Sonia Suter has been a professor at George Washington University since 1999. She earned her B.A. in English with highest honors from Michigan State University and earned an M.S. and Ph.D. candidacy in Human Genetics from the University of Michigan. She graduated magna cum laude from the University of Michigan Law School. Professor Suter teaches Torts, Genetics and the Law, and Law and Medicine, and her scholarship focuses on legal and ethical issues in medicine and genetics. She has written about such issues as the routinization of prenatal testing, genetics exceptionalism, privacy and property protections of genetic information, reproductive technologies and eugenics, constitutional theories of reproductive rights, the commodification of assisted reproductive technologies, informed-consent law, physician-assisted suicide, end-of-life decision making, DNA forensics. She has also worked with policy makers on issues related to genetics and bioethics.

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### **Latanya Sweeney, PhD**

*Chief Technologist | Federal Trade Commission*

Dr. Latanya Sweeney joined the FTC as Chief Technologist in January 2014. There, she advises the agency on evolving technology and policy issues. She is also a professor of government and technology at Harvard University and the founder and director of Harvard's data privacy lab. She has testified before Congress and the European Commission and participated in numerous federal regulatory and advisory committees. She is a fellow of the American College of Medical Informatics. Sweeney holds a PhD in computer science, master's degrees in electrical engineering and computer science from the Massachusetts Institute of Technology, and a bachelor's degree in computer science from Harvard. Dr. Sweeney's research has focused on the de-identification of data, developing privacy technologies, and the protection of health information.

### **Nicolas P. Terry, JD**

*Hall Render Professor of Law | Indiana University Robert H. McKinney School of Law*

Nicolas Terry is the Hall Render Professor of Law at the Indiana University Robert H. McKinney School of Law. He serves as Director of the Hall Center for Law and Health. Professor Terry teaches Torts, Products Liability, Health Information Technology, Law & Science, and Health Care Quality & Safety. Educated at Kingston University and the University of Cambridge, Professor Terry began his academic career as a member of the law faculty of the University of Exeter in England before joining the faculty at Saint Louis University School of Law, where he served as co-director of the Center for Health Law Studies and the School of Law's Senior Associate Dean. Professor Terry's research interests lie at the intersection of medicine, law, and information technology. His recent scholarship has dealt with health privacy, social media and health, big data, and health care fragmentation. He is a permanent blogger at *HealthLawProf* and at Harvard Law School's *Bill of Health*.

### **Ronald S. Walters, MD**

*Associate Vice President, Medical Operations & Informatics | University of Texas MD Anderson Cancer Center*

Ron Walters is an associate vice president of medical operations and informatics at The University of Texas MD Anderson Cancer Center, applying more than 30 years of experience and knowledge at MD Anderson. He is a breast medical oncologist and is responsible for the professional aspects of Clinical Operations including Medical Informatics, the Tumor Registry, the Transfer Center, Managed Care Programs, Uncompensated Charity Care, Clinical Safety and Effectiveness, and the Physicians Network. He serves on multiple institutional committees striving for improvements in patient care, research, and support systems. Dr. Walters received his medical degree from the University of Nebraska College of Medicine and pursued his MBA at the University of Houston. He also holds an MHA in Healthcare Administration and an MS in Management of Computing and Information Services from Houston Baptist University.

### **Nathan Wessler, JD**

*Attorney, Speech, Privacy, and Technology Project | ACLU*

Nathan Freed Wessler is a staff attorney with the ACLU's Speech, Privacy, and Technology Project. He handles cases involving both free speech and privacy issues, with particular focus on threats to Fourth Amendment rights posed by new technologies. He has challenged law enforcement's warrantless access to confidential prescription records in state prescription drug monitoring programs, and has been involved in a number of cases challenging the government's ability to track cell phones without a warrant. Nate previously served as the National Security Fellow in the ACLU's National Security Project, where he sought transparency and accountability for targeted killing and challenged unlawful detention at the U.S. prisons in Bagram and Guantanamo. He is a graduate of Swarthmore College and New York University School of Law, where he was a Root-Tilden-Kern Scholar.

### **Mariann Yeager**

*Executive Director | Healthway*

Ms. Yeager serves as Executive Director for Healthway, Inc., a public-private collaborative leading efforts to advance secure, nationwide and interoperable exchange of health information, and operationally supporting the eHealth Exchange. She has more than 20 years of experience in the health information technology field. Prior to Healthway, Ms. Yeager worked for 5 years on ONC nationwide health information network initiatives and also helped launch and run the country's first EHR certification program in 2006.



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