

An introduction to the contributors

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What follows is a brief introduction to the Special Issue Contributors. I would like to present my great appreciation to each of them for their intellectual labour. I would also like to thank and present high praises for the efforts of my colleague, Dr. Robert Mathews, who led the expeditionary effort to properly orient and develop this Special Issue, and the very important topic it has commendably surveyed.

Dr. Mathews and I had been discussing this theme for many years before the 2015 IUPESM World Congress on Medical Physics and Biomedical Engineering, in Toronto, Canada, when it was decided that a Special Issue was worthwhile producing. However, the efforts to orchestrate and direct the production of this Special Issue were monumental, and much beyond our original expectations. Owing to the simple fact that the Special Issue Contributors live in countries across every populated continent of Planet Earth, and in spite of his excruciatingly pressing schedule, Dr. Mathews spent vast sums of hours

cooperating with Contributors under a “24/7” scheme, to brilliantly organize important interdisciplinary and multi-disciplinary perspectives for the benefit of our worldwide readership.

This volume is not merely a byproduct of providing ‘great vision’ on how we must globally orient ourselves to the proper idea of Privacy and Security of Medical Information, or how to be calibrated to the highly Interconnected and Interoperable Privacy and Security sensitivities in the World, or how to rightly view Privacy and Security tensions in the Digital Age; it is intended to serve as an invaluable and central “*discussion primer*” on the subject. I believe that this compilation will masterfully serve that purpose.

Lastly, as the Editor-In-Chief, I consider that the collection of global views, lived experiences, challenges faced, collection of ideas, and, the splendid transformational, institutional, operational, legal, philosophical, constitutional, and moral angles – presented by the featured “collection” of Contributors, and as they are configured, is unparalleled, and has never before been presented in this way, in any other publication. It remains our hope that it provokes discussions; that it enlightens, and it delights!

This article is part of the *Topical Collection on Privacy and Security of Medical Information*

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Robert Mathews is Distinguished Research Scholar on National Security Affairs and US Industrial Preparedness, and the Director of the Office of Scientific Inquiry & Applications at the University of Hawai'i. He has served multiple US administrations in various Senior National Security capacities. His practical and scholarly intimacy with a range of subjects, such as asymmetry in threat origins; non-proliferation; arms control; urbanization & rise of mega-cities; sanitation & clean drinking water; healthcare finance, policy construction, operations & outcomes administration; assurance of core competence & operational quality in the enterprise; conditions relating to economic 'production & outputs' in the digital age; systems of food production, safety and conveyance; protection of national critical infrastructures; protective schematics for the digitized society & its life essentials; military force protection; warfighting and power projection in the digital domain; ICT-Command and Control and the safety and security of Information Systems has affirmed him a holistic thinker and a national asset. Mathews served as the visionary and principal lead for United States government-wide *Next Generation Information Environment (NGIE)*, activities, which became the basis for foundational and decisive expressions of "Net-Centricity" and "Network Centric Warfare (NCW)" in global US military operations. He is often heard affirming John Muir's Law, that, "when we try to pick out anything by itself, we find it hitched to everything else in the universe".

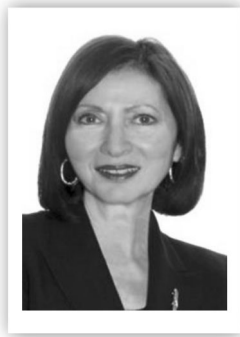
Mathews is a recognized leader in the formulation of interdisciplinary and multi-disciplinary solutions to highly complex operational problems. Simon Ramo, the US Industrialist, Father of the US Intercontinental Ballistic Missile Defense program, and a scientific pioneer of the 'systems approach' typified Mathews as a "spirited fellow-torch bearer for the 'systems approach'". He is the leading authority on the subject of **Interoperability** and the **Integration** of large-scale ultra-complex and highly distributed systems in the world. His pioneering analyses into 'behaviour of complex systems', and 'systems interconnections' have spanned decades and have encompassed political, civilian, military and intelligence systems among others. Mathews' new intellectual

explorations into the challenging area of **Interoperability** is now revealing previously unrecognized factors appertaining to the effective and efficient interoperations of vastly disparate systems.



The Honourable Giovanni Buttarelli is the European Data Protection Supervisor (EDPS). He was appointed by a joint decision of the European Parliament and the Council, on 4 December 2014 for a term of five years. Prior to his appointment, he served as the Assistant Data Protection Supervisor. He is a member of the Italian judiciary with the rank of judge of the Court of Cassation. And, as a Cassation judge in the Italian judiciary, he has long been involved in many initiatives and committees on data protection and related issues at the international level. Before joining the EDPS, Buttarelli worked as Secretary General of the *Garante per la protezione dei dati personali*, the Italian Data Protection Authority, from 1997 to the year 2009.

When implemented, the **General Data Protection Regulation (GDPR)** will be the most comprehensive and progressive piece of data protection legislation in the world – updated to deal with the implications of the digital age. Under the GDPR, the EDPS –responsible for overseeing how EU bodies handle personal information – will along with the many EU Member State Data Protection Authorities (DPAs), be a member of a new European entity for ensuring consistency in how the new rules are implemented and enforced. The International Association of Privacy Professionals (IAPP) recently referred to Buttarelli as, 'one of the most active regulators on the world stage.' Lastly, under designation of the Minister of Foreign Affairs (Italy), EDPS's Buttarelli is a named eminent person, whose experience in the "human dimension" is deemed to be vital to the *OSCE Office for Democratic Institutions and Human Rights (ODIHR)*, where, by his participation, key solutions to specific problems concerning the 'respect of human rights,' and the "human dimension" stand be afforded unequalled address.



Ann Cavoukian is recognized as one of the world's leading privacy experts. She is presently the Executive Director of the Privacy and Big Data Institute at Ryerson University. Appointed as the Information and Privacy Commissioner of Ontario, Canada in 1997, Cavoukian served an unprecedented three terms as Commissioner. In that time, she elevated the Office of the Information and Privacy Commissioner from a novice regulatory body to a first-class agency, known around the world for its cutting edge innovation and leadership. There she created Privacy by Design, a framework that seeks to proactively embed privacy into the design specifications of information technologies, networked infrastructure and business practices, thereby achieving the strongest protection possible. In October 2010, regulators at the International Conference of Data Protection Authorities and Privacy Commissioners unanimously passed a Resolution recognizing Privacy by Design as an essential component of fundamental privacy protection. This was followed by the U.S. Federal Trade Commission's inclusion of Privacy by Design as one of three recommended practices for protecting online privacy. Cavoukian is the author of two books, "The Privacy Payoff: How Successful Businesses Build Customer Trust" and "Who Knows: Safeguarding Your Privacy in a Networked World." She has also written numerous articles and Op-Eds, and has been invited to sit on many Boards.

Cavoukian's expertise has been recognized in many ways. She was ranked among the top 25 Women of Influence, recognizing her contribution to the Canadian and global economy; named one of the top 100 City Innovators Worldwide by UBM Future Cities for her passionate advocacy of Privacy by Design; selected for Maclean's Magazines 'Power List' of the top 50 Canadians; picked as one of the top 10 women in data security, compliance, and privacy; recognized as a Founder of Canada's Digital Economy at IdentityNorth 2016; named as one of the Top 100 Leaders in Identity, 2017; and most recently, Cavoukian was awarded the *Meritorious Service Medal* (Canada) for her outstanding work on creating Privacy by Design and taking it global (2017).



Pompeu Casanovas is Director of Advanced Research, Professor of Legal Philosophy at the Autonomous University of Barcelona Law School (UAB), and founder and Head of UAB Institute of Law and Technology (IDT-UAB). Additionally, he is on the Faculty at Royal Melbourne Institute of Technology, and is a Research Professor at La Trobe University (Melbourne), working for the CRC D2D Programme (Government of Australia). He has served as Principal Investigator in over 50 national, European, and international projects. Casanovas has authored over 10 books and more than 200 scientific articles in the areas of legal philosophy, legal sociology, intellectual history, and AI & Law. His recent publications develop models of governance to implement security, privacy and data protection on the Web, and legal ontologies for semantic interoperability. His research interests comprise both *cyber-security to fight organized crime* and *Online Dispute Resolution (ODR)* and *crowdsourcing to protect rights and foster citizens' political participation*. At present he is building models of 'linked democracy' and 'meta-rule of law' to regulate the Web of Data.



Louis De Koker is a Professor of Law at the La Trobe Law School, Australia. His research in the past few years, noted by International Monetary Fund, the World Bank, the Basel Committee on Banking Supervision and the Financial Action Task Force has focused on managing the relationship between financial inclusion and anti-money laundering and counter terrorist financing objectives, especially in relation to customer data. He has undertaken various research engagements with the bodies such as the World Bank and

AusAID and has worked closely with the Consultative Group to Assist the Poor (CGAP) and with the Financial Integrity Working Group of the Alliance for Financial Inclusion (AFI). This work extended to a range of developing countries including Ghana, Indonesia, Kenya, Malaysia, Namibia, Nigeria, the Ukraine and Palau. In addition to his position at the La Trobe Law School, he is the Program Lead: Law and Policy of the Data to Decisions Cooperative Research Centre. De Koker was the Foundational Director of the University of Johannesburg's Centre for the Study of Economic Crime. He is also a Professor Extraordinarius in Mercantile Law at the University of the Free State and a Visiting Professor at the University of Johannesburg.



Danuta Mendelson holds the Research Chair in Law at the Deakin School of Law. She has authored several books including “The New Law of Torts,” and “Interfaces of Medicine and Law: The History of the Liability for Negligently Caused Psychiatric Injury (Nervous Shock).” she is also the co-author of: “Big Data Technology and National Security: Comparative International Perspectives on Strategy, Policy and Law in Australia, the United Kingdom and Canada” She has also published several book chapters and some 90 peer-reviewed articles published in leading Australian and International Journals. Her fields of research include legal causation; abatement of medical treatment; palliative care and euthanasia; consent to and refusal of medical treatment; confidentiality; malingering and the function of expert medical witnesses; electronic health records; damages; and torts law reform. Mendelson serves on four Editorial Boards, is a Board Member of International Academy of Law and Mental Health (Montreal, Canada); and the Titular Member of the International Academy for Comparative Law/*Academie Internationale de Droit Compare* (The Hague, the Netherlands).



Marta Poblet Balcell is Vice-Chancellor's Senior Research Fellow at the Royal Melbourne Institute of Technology (RMIT). She is co-founder of the Institute of Law and Technology at the Autonomous University of Barcelona and past researcher at ICREA (Catalonia). Her research interests cover different areas of law and technology, open data, crowdsourcing, conflict management and crisis mapping. She is presently conducting research on crowd-sourced civic systems to leverage citizens' knowledge and open data in areas pertaining to law and policy, disaster management, and citizen science. Her academic interests extend into connections between empirical approaches and the different theories of democracy. Her particular area of interest is in how technologies can provide desirable outcomes for citizens in the areas of justice, security, privacy, disaster relief and emergency management. She has published over 40 scientific articles on these topics in various Journals and Books.



David Watts is one of Australia's leading data protection experts. With specializations in information technology, information privacy, intellectual property, governance, and regulatory systems, and as an experienced regulator, policy maker, public and private sector lawyer, he has been able to take on and solve some of Australia's most complex privacy and data security challenges. At the present, Watts is Commissioner for Privacy and Data Protection for the State of Victoria in Australia. Prior to this appointment, he was Commissioner for Law Enforcement Data Security and Acting Privacy Commissioner. Watts is the Australian Delegate to the

UN Global Pulse Data Privacy Advisory Group, and is the Lead to the *Open Data/Big Data Initiative* of the *UN Special Rapporteur on the Right to Privacy*. He is a member of the Faculty at La Trobe and Deakin Universities Schools of Law.



Julia Powles works at the interface of law and technology, with expertise in internet regulation, data protection, privacy, and intellectual property. Her main focus is data and mechanisms for its control, analysis, and governance. In addition to her work on data law and policy, she has a decade of experience in intellectual property law. Prior to her current position as a postdoctoral researcher at the University of Cambridge and Cornell Tech, Powles was a contributing editor and policy fellow at ‘The Guardian,’ and a speechwriter for the Director General of the World Intellectual Property Organization (WIPO). She was awarded a Commonwealth Scholarship to the University of Oxford, and a Cambridge-Australia Scholarship to the University of Cambridge. She has worked in Sydney, Australia for MinterEllison, the Federal Court of Australia, and the Commonwealth Administrative Appeals Tribunal.



Hal Hodson is technology correspondent with The Economist. His reporting focus is on technologies shaping lives of people. Prior to his posting to The Economist, Hodson was a Technology Reporter for the New Scientist.



Brian L. Owsley is a member of the Faculty of Law, at the University of North Texas – Dallas. He has served as the Leonard H. Sadler Fellow for Human Rights Watch in New York City. He has practiced with the Southern Poverty Law Center as a legal fellow in Montgomery, Alabama; the United States Equal Employment Opportunity Commission in Washington, D.C.; and with a private law firm in Washington, D.C., which is now the international firm of Troutman, Sanders. Later, Owsley returned to government practice, working as a trial attorney for the United States Department of Justice in Washington, D.C., and being appointed as a United States Magistrate Judge for the Southern District of Texas, where he served from 2005 until 2013. *While being the United States Magistrate Judge for the Southern District of Texas, he was one of only a handful of US Judges who denied the US Government’s petition for the issuance of a warrant to conduct indiscriminant telephonic surveillance.* With extensive and varied practices and judicial experience, he teaches Torts, and Constitutional Law, among other courses.



The Honourable Jean Philbert Nsengimana is the Republic of Rwanda’s Cabinet Minister for Youth and Information & Communications Technology (MYICT). Before joining the Government of Rwanda, he was Country Director for Voxiva Inc., responsible for building and delivering an award winning e-Health solution in Africa. There, he also managed the implementation of eSoko, a mobile-based Market information system serving more than 2.5 million farmers with real time - market information in Rwanda, winning multiple

awards for being the best e-Agriculture solution in Africa. Prior to that, at Development Gateway Foundation and as the Regional Coordinator for Africa, Nsengimana Coordinated the implementation of e-Procurement and Country Gateway programs in 15 African Countries. Minister Nsengimana is the Chairman-Elect of the *World Summit on the Information Society (WSIS) - Information and Knowledge Societies for Sustainable Development Goals (SDGs)*.

Minister Nsengimana is a ‘believer’ that, “*it is just a matter of time before Africa lifts its ambitions above catching-up with the rest of the world and start leading.*” At least by one key measure, this seems to be coming true. In the World Economic Forum/INSEAD/Cornell University Networked Readiness Index (WRI) for 2016, Rwanda outranked certain other nations in the region and the world, that have far more resources and utility channels at their disposal such as Nigeria, Kenya, Argentina and the Business Process Outsourcing giant - India. As the Minister of Youth and ICT, the Honourable Minister is the lynchpin to the Nation’s ICT based aggressive transformation plans to metamorphose the Republic of Rwanda from an agrarian nation to the Continent of Africa’s most efficient, effective and productive ICT based economy and society. For this Special Issue, Minister Nsengimana candidly traces Rwanda’s ICT transformation by way of reflecting upon the country’s painful histories, and how the ‘lessons learned’, aided by social cohesion and a greater sense of national purpose are enabling the building of essential human rights foundations, to now propel the country forward to a sound and prosperous digital future for Rwandan Citizens.

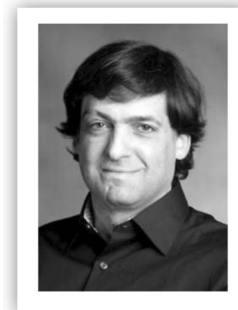


Jane Reichel is a member of the Faculty of Law and at the Centre for Research Ethics & Bioethics at Uppsala University. She is currently the Vice Dean and Chairman of the Research Committee at the Faculty of Law. Reichel’s research focuses on the ongoing processes of globalization and Europeanization of administrative law, the legal discipline dealing with public authorities and their role in the society as well as their relations with individuals. Administrative matters can no longer be addressed solely within one nation state at the time. In her research Reichel addresses how this development affects the role of authorities and how administrative

rules are to be applied in an international context. How can administrative ideals of efficiency, transparency, and legal certainty in decision-making be achieved? How can command and control over administration function in a network of agencies acting beyond the state? An area of specific interest is cross-border data protection, especially medical research and biobanks. Reichel focuses upon the ability of new technologies to collect, store and share large amounts of information giving rise to opportunities and challenges, necessitating administrative solutions that apply across borders.



Björg Thorarensen is Professor of Constitutional law and Human Rights in the Faculty of Law, University of Iceland. She is the author of numerous journal articles and books in the field of constitutional law, international law and human rights. She was Deputy Chairperson of the Negotiation Committee on Iceland’s accession to the EU and chairing the negotiation team on legal affairs –2013. Chairperson of the Board of the Human Rights Institute of the University of Iceland 2004–2013 and is President of the Faculty of Law of the University. Thorarensen is currently the *Chairperson of Board of the Icelandic Data Protection Authority (since 2011)*.



Dan Ariely is, the James B. Duke Professor of Psychology and Behavioral Economics at Duke University and a founding member of the Center for Advanced Hindsight. Ariely, has dedicated his time and efforts to the study of rational and irrational decision-making. His research group, the Center for Advanced Hindsight, conducts retrospective research in

fields such as health marketing, dating behavior and incentive systems. Ariely is a internationally renowned speaker on the subject of *Irrationality*; his TED talks however, are rationally popular. Ariely's documentary "*(Dis)Honesty: The Truth About Lies*" highlights the blurred line between right and wrong, by showing how deceit and deception are universal human traits, and further explores how people deceive both themselves and others. Ariely is the author of numerous bestsellers such as "*Predictably Irrational*" and "*The Upside of Irrationality*," in which he explores behavioral anomalies such as how financial bonuses lessen performance and how people will purchase "free" items despite not actually wanting them in the first place. As an individual who has extensively studied and documented how people act, and why, in this Special Issue, Ariely offers-up valuable perspectives on Privacy related decision-making.



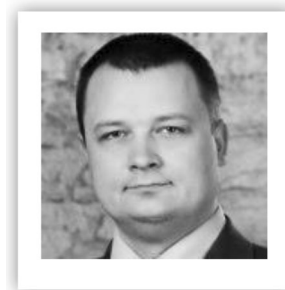
Zoltan Alexin is a leading Privacy and Data Protection expert in his native country of Hungary. Alexin is a member of the Faculty at the University of Szeged with specialization in computational linguistics, information extraction and linguistically aided data mining. Fundamentally, Alexin has advocated that the private sphere is a place where, none should intrude against a data subject's will. He has long argued that in the event of an intrusion, it violates not only the right to privacy, but also the right to human dignity, including the right to self-determination and the right to full bodily and personal integrity. *A long-standing critic of Hungary's Privacy violations, and Hungary's legal and judicial foot-dragging, Alexin has emphasized that Hungary has been very slow in implementing locally, those ethical principles that have already been internationally accepted concerning medical research and human subjects.*

In 2006, he was invited to be an expert delegate to the EuroSOCAP (Development of European *Standards On Confidentiality And Privacy* in healthcare among vulnerable patient populations) research project - funded by the European Commission. In 2007, he became member of the scientific advisory committee of The European Privacy Institute project; and since 2009, he has been a member of the Regional Medical Research

Ethics Committee. Since 2010, he has authored many procedural guideposts on legal, ethical and informatics related questions on personal data protection. In 2009 together with other Hungarian data protection experts, Alexin founded the Association for Fair Data Processing.



Jaan Priisalu is a leading architect of the World's first "e-Society" in the Republic of Estonia, and has been named as one of the leading cyber security experts in the world. In 2007, Priisalu was the Head of the Security Incidents Response Team (SIRT) at Swedbank (the largest Baltic Regional Bank), when the Estonian e-society infrastructure was allegedly attacked by Russian interests. Priisalu has almost two decades of practical experience on the matter of preventing and defending cyber-attacks and has used some of that experience to co-found and Head the Tallinn's Department of the Estonian Defence League's Cyber Unit - an organisation that defends Estonian cyber space. He was the Founding Director General of the Estonian Information Systems Authority; that government authority responsible for all Estonian national information systems. Priisalu is also a Senior Fellow at the NATO Cooperative Cyber Defence Centre of Excellence (CCDCOE) in Tallinn, Estonia's Capital City.



Rain Ottis is a member of the Faculty at Tallinn University of Technology, Estonia. Previously, he was a scientist at the NATO Cooperative Cyber Defence

Centre of Excellence, where he worked on strategic analysis and concept development in the context of national and international cyber security. Prior to that assignment he served as a communications officer in the Estonian Defence Forces, focusing primarily on cyber defence training and awareness. In addition to his current assignment, he teaches cyber security at the University of Jyväskylä, in Finland. His research interests include cyber conflict, national cyber security, politically motivated cyber attacks and the role of volunteers in cyber security.



Luca Belli is Senior Researcher at the Center for Technology and Society (CTS) of Fundação Getulio Vargas (FGV) Law School, Rio de Janeiro, where he heads the Internet Governance @ FGV project. Luca is also associated researcher at the Centre de Droit Public Comparé of Paris 2 University. Before joining CTS, Belli worked as an agent for the Council of Europe Internet Governance Unit, as a consultant for the Internet Society and served as a Network Neutrality Expert for the Council of Europe.

Amongst other publications, Belli has recently authored *De la gouvernance à la régulation de l'Internet*, edited by Berger-Levrault, Paris, he has co-authored the *Net Neutrality Compendium*, and six reports and other official outcomes of UN Internet Governance Forum, amongst which are Recommendations on Terms of Service, and Human Rights. Belli's works have been i.a., quoted by the Organization of American States' Report on Freedom of Expression and the Internet and used by the Council of Europe to elaborate the Recommendation of the Committee of Ministers on Network Neutrality. Belli is the co-chair of the IGF Dynamic Coalitions (DCs) on Platform Responsibility, on Network Neutrality and on Community Connectivity. Lastly, he is co-editor of Medialaws.eu and of the Law, State and Telecommunications Review as well as former Board member of the Alliance for Affordable Internet.



The Honourable Tathagata Satpathy is a Sitting Member of Parliament of the Republic of India. Born into a political family, his mother - as Chief Minister (US State Governor equivalent), together with Mrs. Indira Gandhi, was, one of only a few women in political leadership anywhere, globally. Before securing political office, MP Satpathy was a Journalist; and still owns the Oriya daily known as *Dharitri*, and *The Orissa Post*, an English daily. A Minority Party Whip in the Lower House of the Indian Parliament, Satpathy is a man who is known to speak his mind, and as not being afraid to question the motives behind legislations when introduced. He is known to have famously said the following in the House, in relating to political lethargy and underperformance: *"I am heartbroken to say that the youth of the country doesn't deserve us. We are the most undeserving set of people to be in this House today."*

Satpathy is a staunch constitutionalist, and campaigner for human rights, including strong *Personal Privacy* rights in the digital age. He is a strong proponent for *Net-Neutrality* and a stalwart opponent against India's stout march to widen and deepen activities as a surveillance state. Recently, in a chamber of 545 members, MP Satpathy was the only opposing legislative voice - against the Government of India's efforts to package a constitutionally undermining National Biometric ID program - for nearly 1.4 billion people of the world's population, as a "money bill". For this Special Issue, MP Satpathy informs readers of those supporting facts which caused him to vigorously oppose the allowance of any, and all Indian government support for the deployment of "*The Aadhaar*"; a program that has been classified as the world's largest biometric national ID project - intentioned to unconstitutionally commandeer the highly sensitive personal data of nearly 1.4 billion Indian Citizens, and inappropriately hoarded under government custody, and to be used in unknown ways.



Eneken Tikk is Senior Fellow at the Hague Program for Cyber Norms (Leiden University), where her research focuses on international cyber diplomacy, development of international law with the view of ‘State uses of ICTs’ and the role of emerging technologies in international relations. She has been an advisor at three consecutive Estonian delegations to the UN Group of Governmental Experts on Information Security and provided strategic and legal advice to several other governments on international cyber engagement. Tikk has worked as an attorney in the field of information technology, focusing on EU regulations and standards for security of private and national information systems. Tikk has supported the ICT4Peace international cyber security capacity building activities since 2014 as the course director and lecturer. She is the author of the landmark article “*Ten Rules for Cyber Security*” and the editor and lead author of the “*Evolution of the Cyber Domain: Implications for National and International Security*”.



Diane Roark has had a long history of US Federal Government service, which included postings at the US Dept. of Energy, US Dept. of Defense, US National Security Council, and before retirement, she served in the US House of Representatives, on the

House Permanent Select Committee on Intelligence, as professional staff from 1985 until her retirement in 2002. During her last five years, she was the majority Republican staffer covering the National Security Agency (NSA), reviewing its operations and scrutinizing its modernization program and budget. In a statement on the Floor of the US House of Representatives, Porter Goss, the former Chairman of the House Permanent Select Committee on Intelligence (and later, the Director of the CIA), described Roark in the following manner. He said: “*Diane is known as a very dedicated, tough-minded program monitor who digs into the issues and forces agencies to see and understand what they sometimes miss themselves. She is also known as a very knowledgeable taskmaster, and her arrival at an agency is often anticipated with apprehension.*”

Calling the NSA’s warrant-less domestic surveillance program, “*unethical, immoral, politically stupid, illegal, and unconstitutional,*” Roark had fought hard through official channels to shutter the NSA effort, to no avail. Later, Roark was accused by the US Government of being a source of classified information for a US reporter. After an exhaustive and destructive struggle, Roark was cleared of any wrongdoing. In Roark, the people of the US had a intelligence community and national security professional with highly specialized proficiencies and experience often very difficult to converge.



Pamela (Pam) Dixon is the founder and Executive Director of the World Privacy Forum. She is the author of eight books, numerous articles, and privacy studies, including her landmark *Medical Identity Theft* study. She has testified before US Congress on consumer privacy issues as well as before various US federal agencies. Dixon’s collaborations have yielded the seminal report on predictive algorithms, *The Scoring of America*, and other well-regarded privacy-focused research,

articles, and policy analyses. Dixon and Robert Gellman co-authored a reference book on privacy, titled, *Online Privacy: A Reference Handbook*, and most recently a chapter on privacy regulation and law in *Enforcing Privacy: Regulatory, Legal, and Technological Approaches*. Dixon is also an expert advisor on health data use to the OECD. The World Privacy Forum is a non-profit public interest research and consumer education group that focuses on the research and analysis of privacy-related issues. Founded in 2003, the Forum publishes significant privacy research and policy studies on health privacy, privacy self-regulation, financial privacy and identity issues, biometrics, and data broker privacy practices among other issues. *The Patient's Guide to HIPAA* is a long-standing resource maintained at the WPF.



Robin Wilton is the Technical Outreach Director - Identity & Privacy - for the Internet Society (ISOC). Wilton has over 30 years of experience in the IT industry, in roles including technical and pre-sales specialist with IBM and Sun Microsystems, Gartner analyst, and independent consultant. His IT experience includes work on banking systems, cryptographic and key management products, public key infrastructure, and federated identity management. He has a particular interest in digital identity and privacy, and their relationship to public policy, and has represented ISOC in technical and policy fora such as the OECD, Council of Europe, Internet Governance Forum, and Internet Engineering Task Force. Wilton is also a board member of the Kantara Initiative, where he previously served as director of privacy and public policy.



Luiza do Carmo Louzada is a PhD Candidate in Collective Health at the Institute of Social Medicine (IMS) of the State University of Rio de Janeiro - UERJ. Louzada is a Researcher and a Lawyer with Social and Legal Sciences specializations with experience in the area of Human Rights, Data Protection, Privacy, Bioethics, Genetic Data Protection and Consumer Law.



Molly Schwartz is an Archives, Records and Information Management specialist at the Metropolitan New York Library Council. Schwartz has also served as an analyst at the US Department of State's Bureau of International Information Program, and has worked on digital accessibility and e-government analytics at the US Library of Congress. She was formerly a resident at the Association of Research Libraries.



Aline Holzwarth is staff at Center for Advanced Hindsight (CAH), and Acting Director of the Startup Lab. At CAH, she is responsible for project management, supervision, and conducting specialized studies, grant-writing, and fundraising among other responsibilities.