Information Privacy in the Evolving Healthcare Environment

Edited by
Linda Koontz, CIPP/US, CIPP/G

HIMSS®

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Julie S. McEwen, CIPP/G/IT/US, CISSP, PMP, is a Principal Privacy and Cybersecurity Engineer and leads the privacy capability at the Cybersecurity and Privacy Technical Center at MITRE. She is currently working on privacy research in the healthcare area, and has also supported the U.S. Department of Health & Human Services. Prior to joining MITRE, she managed privacy and cybersecurity programs and advised organizations on policy and technology issues while at the U.S. Department of Defense, Deloitte, IIT Research Institute, the Logistics Management Institute, and T. Rowe Price. She is editor of *U.S. Government Privacy: Essential Policies and Practices for Privacy Professionals*.

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Larry Ozeran, MD, is a surgeon and software developer. He was a UC Davis associate faculty in informatics for three years and an editor of *H.I.T. or Miss* (AHIMA, 2010). He has recorded popular HIMSS podcasts on health IT failure and ARRA and serves on the HIMSS Public Policy Committee. Dr. Ozeran is an AMIA Working Group chair and served on the AMIA Public Policy Committee. He received an award from the State of California for assisting in its response to ARRA, later advising Cal eConnect and CalHIPSO. President of Clinical Informatics, he advises clients on public policy, strategic planning, provider engagement, and clinician training.

Deborah C. Peel, MD, is a leading U.S. advocate for patients' rights to control access to sensitive personal health information in electronic systems. In the United States, the lack of health information privacy causes millions of Americans every year to avoid early diagnosis and treatment for cancer, depression, and STDs. She is also a practicing physician and has been a Freudian psychoanalyst for more than 30 years. She founded Patient Privacy Rights (PPR), the nation's leading consumer health privacy advocacy organization, which defends Americans' rights to health privacy. PPR has 12,000 members in all 50 states. She also leads the bipartisan Coalition for Patient Privacy, representing 10.3 million people. Dr. Peel created and hosts the International Summits on the Future of Health Privacy. The summits bring together national and international experts from advocacy, academia, government, and industry to debate urgent problems and compare solutions. Academic partners have included the University of Texas LBJ School of Public Affairs, the O'Neill Institute at Georgetown Law Center, the University of Cambridge Computer Lab, the Harvard Data Privacy Lab, and the University of Texas School of Information. Dr. Peel was named one of the "100 Most Influential in Healthcare" in the United States by *Modern Healthcare* in 2007, 2008, 2009, and 2011—the first and only privacy expert and advocate on the list.

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—Linda Koontz, CIPP/US, CIPP/G

Introduction

By Linda Koontz, CIPP/US, CIPP/G

As someone who has studied information privacy for many years, privacy in the healthcare domain has always held significant interest for me. First of all, it is *tremendously important* because of what is at stake. According to Centers for Medicare & Medicaid Services (CMS) actuaries, healthcare costs are expected to grow an average of 5.7 percent per year between 2011 and 2021.[1] Further, studies have shown that while the United States spends more on healthcare than other industrialized nations, it lags behind in performance and outcomes.[2,3] These developments make it clear that we must continue to look for ways to improve patient care and the healthcare system itself using a variety of means, including through the adoption of health information technology. However, the ability to successfully leverage the potential of health IT depends to a large degree on the public trusting that their information will be kept private and secure. Secondly, *health information privacy is incredibly complex* and challenging. Electronic health records and the exchange of health information are still in their nascent stages and significant work and original thinking still remain to be done in the coming years to integrate and balance technology, privacy, security, and the delivery of healthcare. The scope of this issue is also enormous, potentially affecting the way that not only every healthcare provider, hospital, and insurer collect, use, and share personal health information, but also how patients will access their own information and ultimately, how they will interact with their healthcare providers.

What I have found over time in studying privacy and advising the federal government on privacy issues is that while individuals clearly value privacy, there is at the same time a great deal of confusion over the subject. We are all familiar with anecdotes of privacy "rules" being used to unnecessarily withhold information from the people who need it. In addition, many mistake keeping information secure—that is, confidential and safe from unauthorized disclosure—as being the same as preserving individuals' right to privacy. Thus, this book is intended to educate a broad audience on the meaning of privacy and the challenges facing our nation as we move to improve our healthcare system. My goal is simply to describe privacy and its associated challenges in the healthcare domain, not only to other privacy professionals who are passionate about privacy, but primarily to physicians and other healthcare providers, people in the business end of healthcare, information technology professionals, policymakers, and patients.

This book is divided into three parts. The first four chapters lay the foundation by exploring the meaning of privacy, the relationship between privacy and medical ethics, the synergy that exists between information privacy and security, and the complex legal landscape governing health information privacy. The middle of the book, Chapters 5 through 10, explore some of the most significant privacy challenges faced by the healthcare community as it seeks to transform itself. The topics span the gamut from health information exchange to consent to secondary use to transparency. The final chapter looks to the future, identifying current trends and providing a view of the changes we might expect to see as a consequence of these trends.

The expert authors of the various chapters in this book represent a diversity of disciplines as well as thought. Among them are physicians, researchers, policy analysts, lawyers, privacy practitioners, and privacy advocates. Given this diversity, however, the reader may note that there are differences in how the various authors describe privacy and in the solutions they are proposing to the challenges that face us. These are not contradictions as much as a reflection of the reality of the multiple meanings of privacy, and that in many ways, we are still at the beginning of a very long discussion on this subject. My hope is that the reader will walk away with a greater understanding of privacy, the issues in healthcare, and an appreciation of the range of viewpoints and options that exist.

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About the Book

Information Privacy in the Evolving Healthcare Environment is a critical book for health professionals or organizations interested in how the rapidly changing U.S. healthcare landscape will affect patient privacy. The book begins by discussing of the meaning of privacy, the relationship between privacy and medical ethics; the synergy that exists between information privacy and security; and the complex legal landscape governing health information privacy. The book then shifts to explore some of the most significant privacy challenges faced by the healthcare community as it seeks to transform itself. T~~he~~ topics span from health information exchange ~~to~~ consent to secondary use ~~to~~ transparency. Finally, the book closes with a look to the future, identifying current trends and providing a view of the changes we might expect to see as a consequence of these trends.

With contributions by leading health privacy experts, *Information Privacy in the Evolving Healthcare Environment* was written ~~and~~ in a style that is easy to grasp for professionals across the healthcare spectrum, including physicians, health IT professionals, administrators, and policymakers.

About the Editor

Linda Koontz, CIPP/US, CIPP/G, is Senior Principal for Privacy and Strategy at MITRE, a not-for-profit corporation chartered to work solely in the public interest, which operates multiple Federally Funded Research and Development Centers (FFRDC~~s~~). In this role, she leads the strategic privacy work for MITRE's Center for Connected Government, advising senior-level staff at federal agencies on strategic approaches to building privacy into their organizations, processes, and systems. She currently advises the Chief Privacy Officer ~~in~~ the Office of the National Coordinator on privacy issues associated with nationwide implementation of health information exchange and manages the activities of the Health Information Technology Policy Committee's Privacy and Security TIGER Team. She has also provided privacy advice and support to the Department of Homeland Security and was recently appointed by the Secretary to the Department's Data Protection and Integrity Advisory Committee (DPIAC).

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