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 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. The topics span from health information exchange to consent to secondary use in 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 (FFRDCs). 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 at 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).

Ms. Koontz has more than 30 years’ experience in information systems management and technology. Prior to joining MITRE, she served as the Director, Information Management for the U.S. Government Accountability Office (GAO). In that role, she directed a broad portfolio of Congressionally-requested studies, producing numerous reports on privacy, information access and dissemination, information collection, and records management. Ms. Koontz also testified numerous times before Congressional committees as an expert witness on these issues. She holds a BA in Accounting from Michigan State University and is a Certified Information Privacy Professional. She is also an Executive Coach and a graduate of Georgetown University’s Leadership Coaching Program.

About HIMSS

HIMSS is a cause-based, not-for-profit organization exclusively focused on providing global leadership for the optimal use of information technology (IT) and management systems for the betterment of healthcare. Founded 53 years ago, HIMSS and its related organizations are headquartered in Chicago with additional offices in the United States, Europe and Asia. HIMSS represents nearly 50,000 individual members, of which more than 900 work in healthcare providers, governmental and not-for-profit organizations. HIMSS also includes over 370 corporate members and more than 225 not-for-profit partner organizations that share our mission of transforming healthcare through the effective use of information technology and management systems. HIMSS frames and leads the healthcare practice and public policy through its content experts, professional development, research initiatives, and media vehicles designed to promote information and management systems’ contributions to improving the quality, safety, access, and cost-effectiveness of patient care. To learn more about HIMSS and to find out how to join us and our members in advancing our cause, please visit our website at www.himss.org.
HIMSS Mission
To lead healthcare transformation through effective use of health information technology.

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Finally, I would like to thank my husband Dan, and my sons Nick and Ryan for their patience and their willingness to just listen.

—*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. Further, studies have shown that while the United States spends more on healthcare than other industrialized nations, it lags behind in performance and outcomes. 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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