Third Edition

Ethical Health Informatics
Challenges and Opportunities

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We dedicate this book to

Our parents and first ethical teachers

Paul William and Gloria Virginia Scott Sugg
Frank and Gabriela Haider

Our caring and compassionate ethical husbands

Gilbert Lee Hoffer
John Lynn Cornelius

Our Families

Dorette Eirene Welk and Charleen Rene Szabo
Gabriele Haider, Ryan A. Cornelius, and Janis E. Cornelius

Our colleagues and students who have informed our professional practice
and challenged us to achieve excellence
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Ethical Health Informatics: Challenges and Opportunities presents an informed discourse on many issues arising from the proliferation of information technology and biotechnology in the delivery and funding of health care in the United States. Ten years have passed since the second publication of this book, and in that timeframe the social and ethical concerns confronting society have expanded. Mapping of the human genome, homeland security, terrorism, bioterrorism, natural disasters, patient safety, medication errors, medical identity theft, hacking of data systems, and accessibility of health care for all have resulted in an increased reliance on information technology to process the massive amounts of data generated by these concerns. However, information technology appears to be both the answer and a potential problem for many ethical challenges concerning the privacy, confidentiality, security, and safety of patient and provider and government electronic information systems.

The societal changes taking place as a result of the above concerns are especially relevant to those individuals who generate healthcare data (doctors, nurses, health practitioners) and those individuals who manage information and technology (health information management and informatics professionals). Today’s challenges require vigilance concerning the right and wrong uses of patient information and appropriate and inappropriate access to it from a much broader perspective than in the past. This requires professionals to assume the ethical responsibility not only to manage, but to protect patient-related data and information resources in whatever form it is contained (paper or electronic), and at whatever site it may be maintained.

These challenges have been eloquently brought to light in the third edition. The book has been expanded to include updated chapters in the areas of professional ethics, uses of information, electronic health records, sensitive information, and consumer and professional informatics. Five new chapters have been added on important topics related to data analytics, information governance, longitudinal health care, information technology and biomedical instrumentation, and future trends and roles healthcare professionals may encounter in the ethical handling of healthcare data and information. An excellent cadre of authors has been brought together to provide an overview and assessment of the ethical issues raised by the increased demands for tertiary and secondary data and information. The authors provide in-depth theoretical and practical discussions on a variety of ethical issues. They address theories and models of ethical practice, along with ethical case scenarios related to selected practice venues. Overall, there are 80 case scenarios to consider along with an eight-step decision-making matrix. The matrix is a wonderful learning tool because it guides the reader in understanding the complexity of problem solving and ethical decision making.
As the healthcare industry continues to adjust to the requirements of the Affordable Healthcare Act (Obamacare), new delivery modes, cost containment, electronic health record systems, the sharing of information between systems, and the use of data for business and clinical analytics, there will be a need to address the ethical handling of healthcare data and information. I am pleased that Ethical Health Informatics: Challenges and Opportunities provides the reader with an awareness and solid foundation for understanding the principles and values so important for the ethical practice of managing healthcare data and information.

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Preface

There are two characteristics of this book that make it unique: the content which focuses on the intersection of health informatics and ethics and the use of a decision-making matrix to analyze issues surrounding the appropriate use of health information. The textbook describes the ethical challenges and opportunities that arise from the growing use of data and information in healthcare. Legal and legislative aspects surrounding the ethics of managing data and information are interwoven throughout the book which serves as a resource for teachers, students and practitioners. This textbook is written to reflect a commitment to interdisciplinary collaboration because many of the ethical issues discussed are not limited to just one healthcare discipline. Overall, the textbook is designed to assist health informatics and information management professionals as well as physicians, nurses, social workers, public health professionals, healthcare administrators, health care professionals, such as, physical, occupational and respiratory therapists, and other related disciplines. This textbook will assist professionals who establish standards for ethical competency and those who want to improve their ethical decision-making skills.

The preface will answer the following questions.

- Who are the authors?
- How are the chapters organized?
- What students will benefit from reading this book?
- What is the decision-making matrix and why is it important?
- How can teachers use this book?
- What is the unique value of this book?

Who are the authors?
The authors include faculty, deans, healthcare professionals from universities and governmental agencies and consultants with degrees and credentials across the continuum of healthcare and health informatics. Each author has identified ethical issues reflective of their experience with the topic along with one or more scenarios to illustrate the issue under discussion.

How are the chapters organized?
This book is divided into six sections: Professional Ethics; Uses of Information; Electronic Health Information; Management of Sensitive Health Information; Consumer and Professional Informatics; and Looking to the Future. Chapters from the 2nd edition were updated and five new chapters were written for this edition, as noted below.

I. Professional Ethics
1. Professional Values and the Code of Ethics
2. Ethical Decision-Making Guidelines and Tools
3. Privacy and Confidentiality
V. Consumer and Professional Informatics
21. Digital Health Technologies for Consumers, Patients and Caregivers
22. Management and Leadership
23. Entrepreneurship
24. Vendor Management
25. Advocacy

VI. Looking to the Future
26. Future Challenges and Opportunities (NEW)

Focuses on potential future professional roles and emerging trends, driven by the explosion of information technology in the healthcare and health information systems and examines how we can educate ourselves and future generations to be prepared to meet these challenges and respond to the opportunities.

What students will benefit from reading this book?
Students enrolled in associate, baccalaureate, masters and doctoral programs in many healthcare related disciplines, including health informatics, health information management, medicine, nursing, healthcare professions, public health, healthcare administration, business and information technology.

What is the decision-making matrix and why is it important?
Ethical issues do not allow the luxury of the right answer based exclusively on laws, standards, or rules. To facilitate ethical decision-making, a matrix has been developed to help readers evaluate and resolve problems based on an understanding of values, professional obligations and multidisciplinary perspectives. The matrix facilitates a more expansive view of a problem and the options for making an ethical decision.

Jacqueline Glover’s chapter, Ethical Decision-Making Guidelines and Tools, includes an ethical
The ethical decision-making matrix is a tool to help you organize complex ethical problems; however, there is no simple fill-in-the-box approach to ethical decision making. The objective is to follow each step of the process and not move from the question directly to what should be done or how to prevent it next time. If you skip steps, you will not fully understand all of the values and options for action. Also, the matrix provided for each scenario is not the only way to examine the problem. You can make an equally compelling ethical argument for a different decision—just be sure to follow all the steps of the matrix.

**How can teachers use this book?**

Ethical decision-making cannot be based on the perspective of one individual. The content in the chapters and the process for analyzing the scenarios, using the matrix, requires team discussions. This textbook can be utilized across-the-curriculum, in conjunction with all of the courses in the professional program. For example, when teaching quality management, faculty can have students read the information on quality management from books, periodicals,
presented in the chapter. For example, if the matrix indicates that information should not be shared on Facebook, the students can decide to make a different decision—as long as they use the 8-step matrix to evaluate the problem and decide what to do.

What is the unique value of this book?

All who work within healthcare and information systems must utilize and combine their technical, professional, and ethical expertise. The management of health information increasingly requires decisions that cannot be made only by applying rules, regulations, accreditation standards or legal mandates. Everyone working in roles that support healthcare and health information will need to make ethical decisions. Students and professionals should consistently expand ethical decision-making skills. Understanding the language and tools of ethics, the values embedded in the various professions and applying knowledge in support of ethical decisions is a rewarding endeavor. If someone learns the ethical language and principles and how to use the decision-making matrix, the identification and defense of multiple perspectives and options for ethical decision-making is possible.

The chapters in this book should generate many energized discussions. Ethical decision-making requires courage. Read the chapters, discuss the content in groups and celebrate the joy and power of ethical decision-making.

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I want to especially thank Gilbert Lee Hoffer, my precious husband. We share the values of gratitude for the gifts of life, the importance of joy and celebration with family and friends, and most important, laughter and love.

Two courageous, compassionate, and intelligent teachers guided my learning about health information and ethics. Louise Huttsell taught me to be passionate about medical records, to always remember the sacredness of the information and to be competent when analyzing, presenting, or releasing health information. Jackie Glover taught me the importance of ethics in my personal and professional life. She is my friend and mentor.

I had the opportunity to work with excellent authors who had the courage to describe the ethical issues for their area of expertise. I was honored to work with these authors, and I thank them for their scholarly and innovative contributions.

In addition to my parents and sisters, I couldn’t sustain life without the support of my brother-in-law, Francis Joseph Welk, and my nephews and their families—Paul Joseph, Courtney, and Ryan; John David, Karen, Sebastian, Sara, and Lilith; Jeffrey Scott, Kim, Brady, and Ethan and Gil’s children and their partners, Aaron and Deborah, Ada, Sophia and Kim. Their love and hugs energize my soul.

Friends and their families celebrate life with me: Sandy and John Bailey; Melanie and Martyn Brodnik; Theresa Duff, Dawn Ferguson; Barbara and Ed Fuller; Merida and Russell Johns; Barbara and Gerald Hrycko; Anita, Lea and Mia Jensen; Gwen Kennedy; Alfred and Elana Michenzi; Lisa, Vince and Elisabeth Morton; Bernard Slosberg and Mary Chor; Jane Wietsma and Scott Gudgeon; Sally Williams; parishioners at St. Paul’s; Thanksgiving holiday friends and many relatives in the Sugg, Scott and Hoffer families.

My colleagues and friends Melanie Brodnik, Cathy Flite, Lisa Morton, and Virginia Mullen are always there for guidance. Charlie and Edie Seashore have left this life and are my spiritual mentors. Charlie taught me to “think purple!”

Mike Brown, my publisher, was always available for my questions, and I absolutely trust his advice. He has been my publisher for all three editions of Ethical Challenges, and he encouraged me to edit this third edition, even though I was “retired.” Nicholas Alakel, Rebekah Linga, and Joyce Ippolito guided the words on the page and the production of the book.

Laurinda Beebe Harman
We are all students and teachers. Today’s dynamic environment requires that of us all. The very nature of contemporary society and the information explosion necessitates that we continually adjust our understanding of the world around us. I wish to take a moment to acknowledge those teachers, mentors, colleagues and students who have contributed to my ethical growth and development and served as the foundational bricks and mortar to help me construct and reinforce my moral fortitude. Without your influence and support, this book would not have been possible.

For me, this book presents an in-depth exploration of important ethical challenges encountered in healthcare and asks some tough, thought provoking questions. Thought provoking questions can spark us think in new and exciting ways. Dr. Elizabeth Smythe (2004) articulates the value of stimulating focused thinking in the following quote:

The very nature of being human means that we cannot not-think. Every person sitting in the classroom will be thinking about something (what others are wearing, how long till lunch, what happened yesterday). Thoughts will always run around our minds, infuse our emotions, and provoke our bodies. We seek thoughts and thoughts seek us. There will be excitement, concern, bewilderment and clarity, perhaps all in the same experience. The charge is not to ‘make thinking happen’ for that is beyond our abilities. The teacher, however, has the chance to capture the focus of the think and invest the thinking time in a quest worthy of thought. Thinking can infuse everything with fresh passion, with bold questions, with radical insights. And it can be as simple as stopping to listen, as simple as asking the right question at the right time (p. 331).

You have instilled in me the courage to ask those difficult questions and encourage others to do the same.

Thank you.

Frances H. Cornelius