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Ethical Health Informatics

Challenges and Opportunities

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We dedicate this book to

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Our Families

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Our colleagues and students who have informed our professional practice
and challenged us to achieve excellence

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Foreword

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.

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The book is an excellent resource for healthcare professionals in a variety of disciplines, such as clinical medicine, administration, public health, health information management, informatics, and ethics. This book provides standards of conduct and ethical practice, thus introducing the student to the basic ethical principles and values of whatever discipline they represent. For faculty, the book serves as a foundation for debate and discussion that will help weave the ethical fiber of tomorrow's practitioners throughout the educational program. For the practitioner, it offers a confirmation of the standards of conduct and ethical uniformity of practice that supports the practitioner's resolve to address ethical issues in a proactive, effective manner. The practicality of the book makes it attractive to all who are drawn into the professional responsibility of generating, using, or managing health information in an ethical manner.

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

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II. Uses of Information

4. Data Analytics (*NEW*)

   Examines the challenges presented by the vast amount of data available, based on advances in technology. Data analysts must consciously attend to the ethical considerations associated with the management of big data.
5. Compliance, Fraud, and Abuse
6. Coding
7. Quality Management
8. Research and Decision Support
9. Public Health and Informatics
10. Longitudinal Coordinated Care (*NEW*)

    Describes the implications of a significant change in health care as the patient becomes a member of the care team across the continuum of the healthcare system. Patient-centered medical homes, longitudinal care and complex care management are explored.
11. Clinical Care: End of Life.

III. Electronic Health Information

12. Electronic Health Records
13. Information Security
14. Information Technology and Biomedical Instrumentation (*NEW*)

    Describes the burgeoning growth of information technology and the increasing adoption of biomedical instrumentation.
15. Information Governance and Management (*NEW*)

    Clarifies how effective stewardship (responsible handling of information) and governance (ground rules for execution of the information) advances ethical information management.
16. Integrated Delivery Systems
17. Digital Health: Health Information Technology and Information Exchange

IV. Sensitive Information

18. Genetic Information
19. Adoption Information
20. Substance Abuse, Behavioral Health and Sexual Information

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

SCENARIO What is the problem to be solved?		
Steps	**Information**	
1. What is the question?		
2. What is my "gut" reaction?	What is your first reaction to this case on an emotional level? What assumptions are you making? What biases do you have?	
3. What are the facts?	**KNOWN**	**TO BE GATHERED**
4. What are the values? Examine the shared and competing values, obligations, and interests of the many stakeholders in order to fully understand the complexity of the ethical problem(s). STAKEHOLDERS Patient, family, HIM professional(s), healthcare professional(s), administrators, society, and others appropriate to the issue.	**Patient:** **Family:** **HIM Professional(s):** **Healthcare professional(s):** **Administrators:** **Society:** **Others, as appropriate:**	
5. What are my options?		
6. What should I do?		
7. What justifies my choice?	**JUSTIFIED**	**NOT JUSTIFIED**
8. How can I prevent this problem?		

decision-making process, which is presented in the matrix. The textbook includes 80 scenarios which have been analyzed using this matrix.

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,

websites and other resources and have the students read the chapter on quality management in this book. Students can be taught the professional content and then discuss the ethical implications of the decisions that must be made. Ethics can be interwoven into all courses so that it can become a standard of practice. This approach can be used for many courses to reinforce and integrate ethical considerations in content areas such as data analytics, clinical decision-making, electronic health record systems (EHRS), information security and management and leadership, to name a few of the courses in professional academic programs. Ethical scenarios can be coordinated with other case studies and learning activities to help students understand how ethics is interwoven in all areas of practice and they can build competencies in the process of exploring the ethical dimensions of professional practice. This textbook can be used in professional courses as noted above and/or in a discipline-specific or multidisciplinary ethics course.

Small group discussions: Most ethics classes combine lecture/didactic with small group discussions. Ethical decisions are analyzed and discussed, using ethical tools and critical thinking. If there are students from multiple academic programs, mix the students up into various groups so that multiple perspectives (personal and professional) can be heard. Understanding the diversity of obligations, values and obligations are essential in the ethical decision-making process. If it is a multidisciplinary course, faculty members from several disciplines can lead the small group discussions. Faculty may also want to reach out to alumni and other practitioners in the area to lead these small group discussions.

Small group or homework assignments: Have the students create the decision-making matrix making equally compelling counterarguments or a decision that is different than what is 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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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. Elizebeth 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

Smythe, E. A. (2004) Thinking, Nurse Education Today, Volume 24, Issue 4, May 2004, Pages 326–332. doi:10.1016/j.nedt.2004.02.008