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Ethics and Health Informatics: Users, Standards, and Outcomes

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After reading this chapter, you should know the answers to these questions:

- Why is ethics important to informatics?
- What are the leading ethical issues that arise in health care informatics?
- What are examples of appropriate and inappropriate uses and users for health-related software?
- Why does the establishment of standards touch on ethical issues?
- Why does system evaluation involve ethical issues?
- What challenges does informatics pose for patient and provider confidentiality?
- How can the tension between the obligation to protect confidentiality and that to share data be minimized?
- How might computational health care alter the traditional provider–patient relationship?
- What ethical issues arise at the intersection of informatics and managed care?
- What are the leading issues in the debate over governmental regulation of health care computing tools?

10.1 Ethical Issues in Health Informatics

More and more the tendency is towards the use of mechanical aids to diagnosis; nevertheless, the five senses of the doctor do still, and must always, play the preponderating part in the examination of the sick patient. Careful observation can never be replaced by the tests of the laboratory. The good physician now or in the future will never be a diagnostic robot. (The surgeon Sir William Arbuthnot Lane writing in the November 1936 issue of *New Health*)

Human values should govern research and practice in the health professions. Health care informatics, like other health professions, encompasses issues of appropriate and inappropriate behavior, of honorable and disreputable actions, and of right and wrong. Students and practitioners of the health sciences, including informatics, share an important obligation to explore the moral underpinnings and ethical challenges related to their research and practice.

Although ethical questions in medicine, nursing, human subjects research, psychology, social work, and affiliated fields continue to evolve, the key issues are generally well

known. Major questions in bioethics have been addressed in numerous professional, scholarly, and educational contexts. Ethical matters in health informatics are, in general, less familiar, even though certain of them have received attention for decades (Szolovits and Pauker, 1979; Miller et al., 1985; de Dombal, 1987). Indeed, informatics now constitutes a source of some of the most important and interesting ethical debates in all the health professions.

People often assume that the confidentiality of electronically stored patient information is the primary source of ethical attention in informatics. Although confidentiality and privacy are indeed of vital importance and significant concern, the field is rich with other ethical issues, including the appropriate selection and use of informatics tools in clinical settings; the determination of who should use such tools; the role of system evaluation; the obligations of system developers, maintainers, and vendors; and the use of computers to track clinical outcomes to guide future practice. In addition, informatics engenders many important legal and regulatory questions.

To consider ethical issues in health care informatics is to explore a significant intersection among several professions—health care delivery and administration, applied computing, and ethics—each of which is a vast field of inquiry. Fortunately, growing interest in bioethics and computer-related ethics has produced a starting point for such exploration. An initial ensemble of guiding principles, or ethical criteria, has emerged to orient decision making in health care informatics. These criteria are of practical utility to health informatics.

10.2 Health-Informatics Applications: Appropriate Use, Users, and Contexts

Application of computer-based technologies in the health professions can build on previous experience in adopting other devices, tools, and methods. Before they perform most health-related interventions (e.g., genetic testing, prescription of medication, surgical and other therapeutic procedures), clinicians generally evaluate appropriate evidence, standards, presuppositions, and values. Indeed, the very evolution of the health professions entails the evolution of evidence, of standards, of presuppositions, and of values.

To answer the clinical question, "What should be done in this case?" we must pay attention to a number of subsidiary questions, such as:

1. What is the problem?
2. What am I competent to do?
3. What will produce the most desirable results?
4. What will maintain or improve patient care?
5. How strong are my beliefs in the accuracy of my answers to questions 1 through 4?

Similar considerations determine the appropriate use of informatics tools.