Chapter XVII
Electronic Health Records:
Why Does Ethics Count?

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ABSTRACT

The development of electronic health records marked a fundamental change in the ethical and legal status of health records and in the relationship between the subjects of the records, the records themselves and health information and healthcare professionals—changes that are not fully captured by traditional privacy and confidentiality considerations. The chapter begins with a sketch of the nature of this evolution and places it into the epistemic framework of healthcare decision-making. It then outlines why EHRs are special, what the implications of this special status are both ethically and juridically, and what this means for professionals and institutions. An attempt is made to link these considerations to the development of secure e-health, which requires not only the interoperability of technical standards but also the harmonization of professional education, institutional protocols and of laws and regulations.

INTRODUCTION

Archaeological evidence suggests that patient records have been an integral part of healthcare since the dawn of civilization. The history of health record keeping is usually presented as follows: In beginning records were made using materials such as clay (Marsiglia, 1966), wax (Brosius, 2003) or string (quipus) (Ascher & Ascher, 1997). Eventually, these were superseded by paper-based records, and in the second half of the 20th century electronic methods of recoding and storage were introduced and began to replace paper-based records. While electronic based records may never completely replace paper-based records, it seems fair to assume that because of their unparalleled

power in facilitating data storage, handling and communication, electronic health records (EHR) will become the dominant form of health records in the future.

When the history of health record keeping is presented in this way, it portrays the development of EHRs as merely another step in the material evolution of the recording medium. It suggests that while EHRs may present an exponential increase in data storage, handling and communication capabilities, they are inherently no different from any of the previous technological developments except in scale. It thereby places EHRs squarely into the tradition of codes, conventions and traditions that have grown up around medical records in general, and it embeds them in a complex web of professional standards, administrative statutes and legal decisions that have been developed for their protection by the medical profession, the legislatures and the courts. This protective screen has traditionally been grounded in the nature of the physician-patient relationship and in the codes that regulate it and therefore has a sound professional basis.

This way of looking at EHRs is not without its attraction because it has the weight of tradition behind it. Historically, the interaction between physician and patient has been construed as quasi-religious in character and as something that should be shielded from prying eyes, and it has always been understood to include medical records. The roots of this tradition are ancient and universal. They go back to Imhotep in ancient Egypt, the Charaka School in ancient India (Chakraberty, 1923) and the Huangdi tradition in ancient China (McDougall & Hansson, 2002). It was taken up by Hippocrates in ancient Greece (Edelstein, 1923), was inherited by Roman and Arabic medical cultures, and survives today in various contemporary codes of medical ethics. The laws, codes, and protocols that have been developed on this basis, therefore, have a firm and universal foundation and make it readily understandable why there should be restrictions on what may be included in EHRs, how access should be controlled, and why issues of security, privacy, communication, storage and manipulation should be considered important. It also makes it relatively easy to see how these restrictions affect the conduct of health-care and health information professionals as well as of the institutions that may be in possession or in control of EHRs. From this perspective, therefore, ethical considerations are relevant for EHRs simply because they are medical records and as such are covered by the tradition of the physician-patient relationship, which is central to healthcare delivery itself.

However, attractive as this perspective may be, it has several drawbacks. First, it fosters the dangerous illusion that tradition can provide ethical guidance for all developments in medical record keeping. This is assumption is warranted only if the underlying logic of the tradition is sufficiently flexible to be able to deal with developments that were not even on the intellectual horizon when the tradition itself evolved. It is questionable whether this holds true for EHRs—to say nothing of developments like e-health which integrally depends on EHRs for its construction and implementation. In fact, given the rapid pace of developments in electronic record keeping, manipulation and communication and the inevitable lag-time between changes in the real world and changes in codes and traditions, a reliance on tradition virtually guarantees that the ethics of EHRs will fail when new developments arise.

Second, if the procedural and statutory provisions that protect records are defined by tradition, they become dependent on professional, legislative, and judicial interpretations of that tradition and on current perceptions of its validity. Therefore the web of protection that surrounds medical records in general and EHRs in particular becomes subject to political and pragmatic concerns that may proceed independently of ethical principles. The USA Patriot Act (2001, rev. 2005) is here a good example. In the post 9/11 climate, U.S. security concerns rose to such a pitch that

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