

Chapter 7.10

Privacy and Access to Electronic Health Records

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INTRODUCTION

The special relationship of trust that needs to exist between a patient and his or her physician has been recognized since the origins of the profession, and the need for doctors to keep confidential any information disclosed to them is codified in the Hippocratic Oath. A distinctive feature of the health records which arises from this relationship is the intimate nature of the information that they may contain; consequently, it is vitally important

to maintain the confidentiality of the records and to protect the privacy of the patients. Privacy has long been recognized as a fundamental right in most western societies (Westin, 2003), and unless a patient can be sure that personal information will not be distributed against his or her wishes, the patient may be reluctant to disclose information that may in fact be crucial to his or her correct treatment (Ford, Bearman, & Moody, 1999; NZHIS, 1995), or he or she may refrain from seeking treatment (Sankar, Moran, Merz, &

Jones, 2003). This is particularly true when health records contain sensitive information concerning issues like drug and alcohol problems, sexual behavior, mental health, or a genetic predisposition towards certain diseases. In such circumstances, the consequences of the inappropriate release of information could be extensive and might impact on many aspects of a person's life, such as the ability to gain employment, to maintain a marriage, or to obtain loans or life insurance (Chadwick, 1999; Woodward, 1995).

Within the healthcare sector there is a constant pressure to balance patients' requirements for personal privacy against the potential benefits that may accrue to society as a whole from the more widespread use of their personal information. This issue is particularly relevant in developed countries that have been seeking to use computer-based patient records (CPRs) (Dick & Streen, 1991), electronic medical records (EMRs), and electronic health records (EHRs) to improve both organizational efficiency and the quality of care provided for patients (AHRQ, 2006).¹

The potential benefits of EHRs are widely accepted, but there are also serious problems concerning the potential threats to patient privacy (Carter, 2000). The move from paper-based records to electronic records has greatly increased the potential threats to patients' privacy in two ways. Firstly, it has increased the risk of unauthorized access to patients' information by people both within and outside of an organization, since it is now no longer necessary to manually search through individual patient's records and it is possible to systematically search through collections of records from a distance (Goldschmidt, 2005). Secondly, the development of communications networks has greatly increased to the extent to which patient information is now routinely exchanged between different healthcare organizations so more people have access to it (Kissinger & Borchardt, 1996).

This article will explore some of the privacy issues associated with the development and use of EHRs. The first part describes the background and development of EHRs and the various ways

that patient health information can be used and distributed within modern healthcare systems. It discusses the benefits that may accrue to the individual patient and also to healthcare organizations due to improved access to information. The second part then reviews some issues that arise from the use of EHRs, and it reviews research into patient attitudes towards the distribution of their health information. The final part of the article discusses some technologies that address the security requirements of patients such as role-based security systems (Sandhu, Coyne, Feinstein, & Youman, 1996), smartcard systems (Rienhoff, 2003), and finally, e-consent systems (Coiera & Clarke, 2004; Galpottage & Norris, 2005; Scott, Jennett, & Yeo, 2004), which aim to provide patients with much greater control over the access to their information.

BACKGROUND

Electronic information systems are often justified on the grounds that having access to more complete, accurate, and timely information facilitates better decisions. In the case of health records, these benefits may accrue directly to the individual patient in terms of better treatment or to the population in general through improvements to healthcare practice or administration (Mount, Kelman, Smith, & Douglas, 2000). The application of data-mining techniques to large numbers of EHRs could facilitate epidemiological and evaluative studies (Bath, 2004; Payton, 2003), and the information may also benefit healthcare administrators and managers by providing them with more comprehensive information about service usage and costs (Hannan, 1999).

Despite the wide range of their potential benefits, the introduction of comprehensive EHRs has been relatively slow because of the complexity of the health sector from technological, organizational, and ethical perspectives (Goldschmidt, 2005). The use of computer-based information systems to store patients' records has been evolving since the 1970s. The early systems tended to

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