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 focus on the administrative details of a patient and to deal with a single episode of care. Because of the high development and implementation costs, early systems were mainly used in larger hospitals (Goldschmidt, 2005; Reichertz, 2006), but as computing costs have fallen, sophisticated systems have become widespread, and systems are now found in most hospitals and in many primary care or GP practices (Didham & Martin, 2004).

In the late 1980s and throughout the 1990s, the potential benefits of an integrated lifelong electronic health record began to be recognized and explored (Haux, 2006). For the individual patient, major benefits arise from the improved continuity of care which is possible if all healthcare practitioners have a complete and detailed history of the patient's conditions and treatments on which to base their diagnoses and decisions. Easy access to a comprehensive patient history would be particularly useful when a patient is referred to a practitioner for the first time, if a patient needs treatment when he or she is traveling and is away from his or her usual practitioner, or in accident or emergency situations when the patient is unconscious or unable to answer questions (Mount et al., 2000; Hunt, Haynes, Hannah, & Smith, 1998). For example, comprehensive records will improve medication management by allowing the practitioner to quickly check whether a patient is known to be allergic to a particular medicine, or whether a particular drug might have adverse interactions with other medicines the patient may be taking (Ministry of Health, 2001).

Unfortunately, the widespread introduction of EHRs has been hampered by organizational problems caused by the dispersed nature of the healthcare sector in most countries. Since many organizations are involved in providing and funding care, a patient's information tends to get fragmented and dispersed (Goldschmidt, 2005; Kissinger & Borchardt, 1996). Treatment of a typical condition may involve a patient visiting a community-based practice, such as a general practitioner (GP), consultations and treatments by hospital-based specialists, and tests and analyses undertaken by various laboratories. Typically, information from each of these encounters will be stored by each organization within its own separate computer system, which will have been designed to support the specific requirements of each organization and its users. Furthermore, the payment for all these services may come in part or full from several sources, such as the patient, the government, or some private insurance scheme, so further inter-organizational information exchange is required to sort out the finances (Kissinger & Borchardt, 1996). Current developments of EHRs are therefore focusing on distributed structures with a centralized summary of a patient's information, with links to detailed information located in other computer systems (AHRQ, 2006). Developments of this kind are currently being supported