

Chapter 11

Will Privacy Concerns Derail the Electronic Health Record? Balancing the Risks and Benefits

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ABSTRACT

The introduction of information technologies and the electronic record in health care is thought to be a key means of improving efficiencies and effectiveness of the health care system; ensuring critical information is readily available at the point of care, decreasing unnecessary duplication of tests, increasing patient safety (particularly from adverse drug events), and linking providers and patients spatially and temporally across the continuum of care as health care moves out of the traditional hospital setting to the community and home. There is a steady movement in many countries towards eHealth and a fully implemented, in some cases, pan-regional or pan-national electronic health record. A number of barriers and challenges exist in EHR implementation. These include lack of resources (both capital and human resources), resistance to change and adoption of new technologies, and lack of standards to ensure interoperability across separate applications and systems. From the public's perspective, maintaining the security, privacy, and confidentiality of personal health information is a prominent concern and privacy of personal health information still looms as a potential stumbling block for the implementation of a comprehensive, shared electronic record. There are some steps that can be taken to increase the public's comfort level and to ensure that these new systems are designed and used with security and privacy in mind.

INTRODUCTION

The introduction of information and communication technologies (ICT) and the electronic record

in health care is touted by most as a key means of improving efficiencies and effectiveness of the health care system; ensuring critical information is readily available at the point of care, decreasing unnecessary duplication of tests, increasing patient safety (particularly from adverse drug events),

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and linking providers and patients spatially and temporally across the continuum of care as health care moves out of the traditional hospital setting to the community and home (Bates & Gawande, 2003; Health Canada, 2001; IOM, 2001). Whether these benefits are realized remains to be seen, but there is a steady movement in many countries towards eHealth and a fully implemented, in some cases, pan-regional or pan-national electronic health record.

A number of barriers and challenges exist in the implementation of such an ambitious project. These include lack of resources (both capital and human resources), resistance to change and adoption of new technologies, and lack of standards to ensure interoperability across separate applications and systems, to name a few. From the public's perspective, maintaining the security, privacy, and confidentiality of personal health information is a prominent concern. A recent survey of Canadians indicated that they would support the development of an electronic health record but not at the expense of personal privacy (EKOS, 2007). The National Health Service (NHS) in the UK has just completed an extensive public consultation on privacy after backtracking on its opt-out policy for electronic records¹. President Barack Obama's economic stimulus package to build new infrastructure included \$20 billion for plans to link doctors and hospitals with new information technology but was attacked in a bitter dispute over how to protect the privacy of electronic medical records. Consumer groups and patient privacy advocates, the health care industry and lawmakers have been unable to agree on privacy safeguards that would allow individuals to control the use of their medical records for both primary care and secondary uses (e.g. planning and management of services; research and statistical analysis; and fundraising)². Similar concerns over privacy and the adequacy of security measures for electronic records are echoed in other countries across the world (e.g. New Zealand, see Chhanabhai & Holt, 2007).

Thus privacy of personal health information still looms as a potential stumbling block for the implementation of a comprehensive, shared electronic record. There are some steps that can be taken to increase the public's 'comfort' level and to ensure that systems are designed and used with security and privacy in mind.

DEFINITIONS

To set the stage for this discussion a few definitions are necessary.

The ***electronic health record*** represents the longitudinal lifetime record of an individual's encounters with the health care system and various health care providers, residing within a computerized architecture. It includes information in different formats, for example, text, voice, and digital images. This information, such as, demographic data, clinical data and diagnostic results, alerts, reminders, and evidence-based decision-making support is accessible to authorized users based on the user's role and relationship with the patient. Other terms may refer to an ***electronic patient record***, the institutional record of patient encounters, or the ***electronic medical record***, the physician's office record of care. The electronic health record is seen as the linked multi-user, multi-facility, multi-purpose record connecting the institutional (the EPR) and provider level (the EMR) records to provide the comprehensive lifetime record (Nagle, 2007).

Personal health information is information collected on the physical and mental health of an individual and the health services they receive. Within the Health Insurance Portability and Accountability Act legislation (HIPAA 1996) in the United States the term "protected health information" is used to designate all "individually identifiable health information"³ held or transmitted by covered entities under the Act, in any form or media, whether electronic, paper, or oral. This is in distinction to "de-identified health

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