Chapter 1

The Impact of the Global, Extensible Electronic Health Record

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With the arrival of the “World Wide Web,” we have witnessed a transition toward a truly global perspective with respect to electronic health records. In recent years, much more discussion has focused on the potential for international virtual electronic health records and what is required for them to become a reality in the world today (Kilman & Forslund, 1997). As the Internet becomes more ubiquitous and Web-enabled, we see access to electronic health records using these technologies becoming more commonplace. Even so, these Web-enabled health records still remain technologically isolated from other medical records in the distributed continuum of care; much of the standardization challenge still stands before us. We have witnessed startling technological advances, but we still face considerable obstacles to the goal of having globally standardized electronic health records.

In this chapter we describe some of the issues associated with Web-enabled health records, the role of standards in the evolution of Web-enabled health records, and some of the barriers to the development of globally accessible electronic health records. We discuss possible ways to overcome these barriers and the kinds of benefits and opportunities that global health records will help provide. The global scale perspective makes more evident the very real and potentially tragic consequences of prolonged and unnecessary delays in deploying these technologies. Therefore, in an effort to promote a fuller consciousness of health safety, the chapter concludes with a comparative look at the negative impact of impediments in the movement toward global extensible electronic health records.

BACKGROUND

The early years of health informatics were dominated by health information systems running on mainframe computers and minicomputers at large medical facilities (Collen, 1995). These involve significant expenditures to support large central data repositories. These may efficiently solve the needs of the local hospital, but they are difficult to modify, have primarily proprietary interfaces and data representations, and provide little, if any, ability to extend them into new areas without major expenditures. We characterize this state of healthcare information technology as a “stovepipe” industry with relatively limited communications between facilities and little motivation to communicate. HL7 (Health Level Seven, 1999), one of the dominant standards developing organizations for health related information, has provided an important data interchange capability. However, HL7 still has interoperability limitations that result in proprietary implementations utilizing interface engines to meet the need of connecting smaller systems into the domains of the large mainframe repositories. HL7, itself, was founded in 1987 and is an ANSI (American National Standards Institute) accredited Standards Development Organization (SDO). The term Health Level Seven comes from the seventh, or application, level in the ISO (International Standards Organization) communications model for Open Systems Interconnection (OSI).

With the evolution of distributed computing technology, paved by the rapid adoption of Web technology, the need for a central system becomes less compelling. Moreover, with the advent of privacy concerns recognizing the patient’s right to control his/her medical record (Shalala, 1997), the notion of a single healthcare institution maintaining the complete medical record becomes less likely. The need for data to be shared through a secure referral process and the increasing need for a longitudinal medical record to establish long-term effects of slowly evolving diseases such as Hepatitis C and HIV, not to mention management for chronic illnesses like diabetes, pushes one away from the “stovepipe” model to one in which data exchange becomes the central paradigm.

The evolution of the Web (WWW) has helped break down these “stovepipes” by making it almost trivial to publish a database on the Internet (cf. Mactaggart, 1999). For a very low cost one can use a simple “application server” to create a Web presence for a clinical repository. The low cost results in the development of thousands of medical repositories offering the capability of managing some portion of a patient’s data. This includes numerous examples of Web technology being used to manage teleconsultations. However, these developments don’t really provide the patient access to a longitudinal medical record that they could understand. One would have to use an Internet search engine to assemble the long-term medical record of a patient in this distributed healthcare treatment world, although this, in fact, is not practical from a security standpoint. Additionally, this approach has essentially no architectural design behind it and thus is at best an ad hoc solution to the medical record problem with unknown scalability and extensibility capabilities. So how do we resolve this problem?

STANDARDS

How should we link the Web of health records together? The easy publication of electronic health records enables an organization to make information available to patients,
Remote Follow-Up of Implantable Cardioverter Defibrillators: Technology, Patient Management, Integration with Electronic Records, and ICD Product Surveillance