Realizing the Potential of Healthcare Information Technology to Enhance Global Health*

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Abstract. For much of the world, truly productive and functional Electronic Health Record Systems (EHRs) remain an elusive goal of the future. Opportunities abound from the visibility provided by the availability of Health Information Technology funding in the U.S. and other countries of the world. Now is the time to seize the initiative to move from the past to the future to design HIT systems that meet the specific needs of each nation of the world in a way that is obtainable and affordable, and that provides an immediate return on investment. We need to move from an electronic system based on the paper-system to an empowering system based on available technology. We need to recognize that the EHR is not just for data storage but needs to become an intelligent, active partner with the healthcare provider and the patient to enhance health. This paper describes the current state of EHRs and addresses challenges for moving into the future.

Keywords. health information technology, electronic health records, standards

1. Introduction

Although the words “Healthcare Information Technology” were not used, computers have been used in the healthcare area since the early 1960s. The focus of use (certainly in the United States) was for billing and other administrative purposes and then including service-related functions such as admission and discharge, laboratory test ordering, materials management and other functions related to what was called a Hospital Information System. These systems were implemented on large mainframe computers, and the high cost of such systems restricted their use primarily to large hospitals. Health care providers were highly insulated from such systems.

The advent of the minicomputer reduced the buy-in cost, and available functionality spread to departmental systems such as laboratory information systems, radiology information systems, pharmacy information systems, and other small departmental systems. Although most of these systems operated in inpatient settings, a few applications began to appear in the outpatient settings in the early 1970s. These systems operated independently from the large HISs, and data transferred between

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systems was largely manual. For the most part, health care providers were still isolated from the computer.

Microcomputers, or personal computers, became available in the late 1980s and the low investment cost made computer systems available to thousands of people in the healthcare community. Beginning in the early 1990s, applications became available for many healthcare workers, and the concept of a computer-based patient record became widely accepted. With the advent of the personal computer, pressures increased for the healthcare provider to directly interact with the computer to document care and access knowledge and data about the patient. The Institute of Medicine, in 1991, published *The Computer-Based Patient Record: An Essential Technology for Health Care*, but the second edition, published in 1997, noted that little progress had taken place in the six years between those publications. Over the intervening years to the present, progress has been slow, although many countries have published statistics that state that over 95% of primary care providers use an electronic patient record. An important question is to what extent has the use of computers in health care increased safety, improved quality of care, and decreased the cost of delivering care.

This paper discusses the current state of the electronic patient record, the current focus on the collection of data for that record, and then expands to the broader concept of the use of that data in the application of healthcare information technology (HIT) to enhance global health.

2. The Current State of Healthcare Information Technology

Even after a history of almost 50 years, the development of the use of computers in healthcare – Healthcare Information Technology – is still lacking in delivering its perceived potential. The reasons are many: the lack of definition and clarity of what is important and required in health care; the lack of consistency in the practice of medicine; the variety in evidence in an evidenced-based-medicine delivery model; the lack of a business model that proves a return on investment for HIT; lack of standards to support interoperability across various sites, domains, and models for health care; and the lack of an infrastructure enabling the necessary connectivity to support the bringing together of data about a single patient.

For most of the global community, national goals support the concept of a patient-centric record for documenting patient care. In an expanded role, that concept has extended beyond acute care documentation to chronic disease management, to wellness support, to preventive care, and now into preemptive care – the use of genomic data to predict and manage risk for a potential disease. To reflect these wider goals, the most typical name given to this electronic documentation of care is the Electronic Health Record (EHR). In the United States, since 1990, the federal government and the President, specifically, has supported the concept of developing a patient-centric EHR for every citizen of the United States. Earlier this year, President Obama announced the American Recovery and Reinvestment Act. Title XIII of that Act, the Healthcare Information Technology Economic and Clinical Health (HITEC), made available $19 billion dollars that has been increased to $36.5 billion with returned savings for HIT. Some of that money will be given directly to healthcare providers who have employed an EHR in a “meaningful use.” The Office of the National Coordinator for HIT is currently defining what that term might mean and how to measure it. The global visibility of that level of funding plus the funding of the National Health Service in the
United Kingdom, the Infoway funding in Canada, and the funding for HIT in many other countries has drawn world attention to this venture.

2.1. How Did We Get Here?

The evolution to what we now call the EHR has had multiple pathways. For the most part, today’s model for the EHR has been derived from the database resulting from HISs. It contains demographic data, laboratory results, some form of medication data, and details from the inpatient stay or outpatient visit. In some cases, the record included a stylized list of patient diagnoses or a problem list. The primary purpose of the record, beyond patient billing, was a documentation of the patient’s care. The data contained was primarily free text narrative and had little value to drive decision support algorithms or any computer-readable functionality. For the most part, today’s EHR is a poor duplication of the paper record – still unstructured and unorganized containing unstructured content.

There have been many attempts to define the EHR. The IOM definition, in 1991, was “The patient record is the principal repository for information concerning a patient’s health care. It affects, in some way, virtually everyone associated with providing, receiving or reimbursing health care services. A computer-based patient record is an electronic patient record that resides in a system specifically designed to support users by providing accessibility to complete and accurate data, alerts, reminders, clinical decision support systems, links to medical knowledge, and other aids.” Other groups, including the International Standards Organization, have created similar definitions. Even this limited definition has not been met by most of today’s systems.

2.2. Standards for Creating the EHR

Almost all standards and development activity today have been focused on defining the process for HIT, defining the data, collecting the data, and exchanging the data both from departmental systems within the enterprise and between systems outside the enterprise. Some additional standards have been created for decision support, to define required EHR functionality, for security and privacy, to provide linkage connectivity between systems, and documents for data interchange. A number of Standards Developing Organizations (SDOs) now exist that produce conflicting and redundant standards, initially driven by some domain focus and expertise as well as different geographical orientations. The goal, today, is to produce and use a full suite of standards to enable interoperability for healthcare systems, ideally globally. We are not yet there. The case for a single, common vocabulary is even more confused by the existence and use of several hundred different controlled terminology systems. Current efforts to resolve this situation are, fortunately, making progress.

2.2.1. Systems Planning

A number of methods and standards exist for defining the processes and requirements for the use of HIT in various settings. Unfortunately, most existing systems of today have not used this approach to designing systems. Standards and approaches include defining use case, scenarios and story boards to illustrate and document an understanding of what is required in various setting, including identifying the actors,
2.2.2. Data Elements

A number of groups are defining data elements, based loosely on the ISO 11179 standard. As of yet, there has been no harmonization of data element definitions, a unique coding structure, unambiguous definitions, data types, units, value sets, and a number of other attributes. As previously mentioned, there are a number of controlled terminologies in use throughout the world with leading candidates for global use including the International Healthcare Terminology SDO’s SNOMED-CT, LOINC, RxNorm for drugs, International Classification for Disease (ICD) – 9 and 10, MedDRA for adverse events, several nursing terminologies, and several other terminologies and ontologies that have a following. Until there is a globally-accepted repository of common data elements with a standardized and complete set of attributes, true interoperability will be impossible. The creation of such a set will require cooperation among countries, organizations, SDOs, and stakeholders (particularly from the clinical community).

Structures built from atomic data elements (single meaning) need to be common as well. Some of these structures are simply compound structures (blood pressure, for example) or computed data elements (such as Apache Score or Body Mass Index). Structures may grow in complexity such as an asthma workup or a well-baby workup. Multiple groups are now defining structures with both conflicts and overlaps. There is also no consistent use of syntax.

The use of a common Reference Information Model and common data models such as BRIDG provide a common reference point from which to build reusable structures in a number of settings.

Putting together data structures continue in complexity to include clinical statements – logically correct statements for clinical use – to the clinical document architecture. Health Level Seven’s Clinical Document Architecture is being used globally for a number of domain-specific purposes, including the Continuity of Care Document (CCD) or a patient summary record, discharge summary, radiology reports, referrals, infectious disease reporting and other schema-driven report structures.

2.2.3. Data Interchange

Data interchange, or messaging standards, permits an interoperable data interchange among disparate groups. HL7 v2.n or the model-based v3.0 is the most common standard used for the exchange of clinical data. The DICOM standard is used for image exchange. Several specialty standards, such as the National Council for Prescription Drug Programs (U.S.) for exchanging drug prescription data, X12N (U.S.) for exchanging claim data, and CDISC for research and clinical trial data and others.

2.2.4. EHR

HL7 has created standards for defining the required functionality for EHR systems and has expanded the scope of the standard to define other requirements for different views of the patient record including the Personal Health Record. ISO TC 215 has and is creating standards that define the EHR and is contents and organization.
2.2.5. Other Standards

Standards for security and privacy are a must for the public acceptance of EHRs. Other standards include standards for decision support: Arden Syntax and GELLO, guideline standards (GLIF and GEM), the InfoButton, and others. IEEE has defined standards for medical devices including all forms of interfaces between medical devices and systems. New efforts include standards for personal health devices. Standard identifiers, including unique personal identifiers are essential for the aggregation of health data across disparate sites.

3. Enhancing Global Health

How can the power of today’s technology be used to enhance global health? Over the 50 year history of the development of HIT, technology has made remarkable strides in producing fast, economic and almost unlimited storage and computing power. Satellite communication and wireless applications provide connectivity and accessibility around the world with only slight delays. We need to take advantage of this power to increase the resources available to address global needs in healthcare.

HIT addresses a moving target. Changes in technology, changes in knowledge, and changes in requirements have advanced more rapidly than our ability to change. We develop a five year plan only to find the landscape, and consequently, the requirements have changed, making our plans less than effective or even appropriate. Our thinking is still constrained by the past; we must step out of the present and design for the future. Our world also has expanded during this period. We now must consider linked healthcare systems and products over states and provinces, over regions and nations, and over both the developed and the developing countries. What systems, processes and tools are common over this landscape? What is reusable and interchangeable, and how do we identify processes and steps that will work for all?

Challenges

The first challenge that must be overcome is a shift in view from the concentration on just putting data into the EHR. The current EHR is mostly an electronic version of the paper-based system. Data is stored electronic as documents, largely organized around how the data was captured. Rather than viewing the EHR as a destination, it must be viewed as a beginning. The power for enhancement of global health comes only from an effective use of the EHR. As the EHR grows in size, intelligent filters must be developed to provide need-based and event-driven views of the data. Query is the method through which the true value of the EHR can be realized. It is easy to put data into the EHR; it is difficult to access that data in a meaningful way. The architecture of the EHR must support easy and rapid retrieval of data; the architecture of the EHR must be independent of the input and presentation of data. Reuse of data for multiple purposes is a must to realize fully the ROI of the EHR.

The second challenge is designing the infrastructure to support the aggregation and sharing of data across the healthcare environment – that need becomes global. Systems must be designed to support local needs, but the fact that patients’ care is given in a number and variety of settings requires a regionalization of data. My belief is that regional-based centralized Health Information Interchange (HIE) databases can best
serve those needs. National Health Information Networks (NHIN) provide value through connectivity to those systems. The authority for the mandates for the use of infrastructure, for the use of standards and conformance, and for the sustainability of such networks, will require a commitment and funding by governments – even in the poorest of countries. The rewards of such a commitment will soon return the costs as well as improvement in health of the population.

The third challenge is in recognizing what to do in creating the HIEs and NHIN that are first realizable and secondly provide instant value. This challenge requires an understanding of the current state of HIT in the region of interest, what are the critical and immediate problems, what resources are available, and how the work must be managed and progressed. Although sharing across nations and organizations is critical and mandatory for success, each application, system or nation must be viewed as a distinct entity. For the United States, an immediate problem that must be addressed is how to move from the multi-aged and multi-functional installed base to a complete, connected and interoperable system. In a developing country, it may be the absence of electricity and no connectivity. The priority in one country may be establishing a demographic database to understand who is a citizen, where they live, and other social parameters. In another, moving to a common set of data elements to help understand disease prevalence and geographic location of health problems may be the primary problem. Identification of diseases and the spread of disease is a critical factor in improving health care.

Other challenges, in all countries, include capacity-building and sustainability. In the U.S., estimates are that at least 100,000 individuals need to be trained in medical informatics over the next few years. In developing countries, individuals must be trained to provide the capacity to implement, support and use HIT. The process must be done in reasonable steps with a common vision and destination well defined. Each step must bring a visible reward, and progress must be steadily forward. The complete set of stakeholders must be defined and engaged – and that really means the total population in some form.

4. Conclusions

The opportunity to take a giant step, globally, in using HIT to enhance global health is now. The focus of the world is on HIT; we must move quickly and forcefully to take advantage of this situation. Key is the commitment of governments in leadership and finances. While resources, knowledge, and systems must be shared globally, each solution must meet immediate national needs.

If we create the patient-centric EHR that provides an aggregated set of comprehensive data for both patient and provider, and that includes connectivity at local, regional, national and global levels, then we can better understand and respond to public health needs, global health surveillance, prediction models for health care, focus of clinical research, and processes to improve the health and quality of life for the citizens of the entire world. To accomplish these goals, we, the HIT community, must come together as a global workforce. We must adopt common goals, eliminate duplicative efforts, and embrace team efforts. The global community awaits.