A Framework for Personal Health Records in the Philippines

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Abstract

The advent of Internet technology has made it easier for consumers to participate in the management of their own health records. Add to this the proliferation of person-based devices that allow consumers to hold on to electronic copies of their health data (e.g., in their cellphones, PDAs, flash drives). Traditionally, health records have been maintained in hospitals, and patients could only access them on a per request basis (often in the form of a photocopy of the original). The new emerging technologies (Internet, XML, flash memory, mobile computing, etc) already enable consumers to store copies of their own CT/MRI scans and laboratory results in their personal storage devices which they can bring with them as they transfer from one facility to another. As more modalities automate the digitization of health data and make these portable, the more we foresee consumers demanding access to their personal records and asserting their rights to manage their own data themselves. Certainly, there are numerous issues that accompany such a dramatic shift from the conventional. Foremost would be the security and integrity of the data as they are stored in media that are prone to tampering. Another would be the issue of identification and authentication both of the patient and of the provider who would be accessing the data. Resistance from providers is expected as personal health records would require them to invest heavily on infrastructure. Last but not the least, integration of the health records, parts of which may be in different facilities aside from the patient, remain a serious challenge to personal health record systems. This paper proposes a framework for the adoption of personal health records in a way that allows policy makers to manage the transition from conventional to electronic health records in a secure yet cost-effective way using a patient-centric approach. If the bottomline is greater participation of patients in their own care, a thorough analysis of the

strengths and weaknesses of personal health records must be made to facilitate the inevitable shift from provider- and facility-centric care to one that revolves around the one who truly counts --- the patient.

Introduction

The twenty-first century has been called the Information Age and it promises to revolutionize the health sector. With the lowering cost of hardware and the advent of open systems interfaces, it is now possible for individuals to participate more actively in transactions that concern their private information. In no other domain is this participation more relevant than in health, where intimate and personal data need to be exchanged with providers and facilities to effect the most cost-effective approach to the resolution of any health issue.

Conventional health record management the Philippines mostly follows a facility-centric or provider-centric model where the data are stored in paper records in the clinic or in the hospital. This system essentially constrains the patient into returning to the same provider every time because their data is most complete in that facility. If they decide to transfer to another facility, they have to request for a photocopy of their record from the provider. This photocopy is often incomplete and for health data that are not text-based such as radiology and pathology images, the receiving facility usually requests for repeat examinations so they can have a copy of their own. This results to greater expense for the patient.

Recent developments in health information technology are changing that. All of them increase the ability of patient/consumers to participate in the management of their health data. First is the wide availability of person-based computing devices such as cellphones or any device with flash-based memory. These devices have matured to the point that their storage and computing power give them as much capability as desktop computers. Aside from cellphones, there are flash-based memory devices (such as Universal serial bus [USB] thumb drives[1]) which can store volumes of digital information. The USB port specification has opened numerous possibilities for health data capture[2]. The USB drives enable patients to have portable copies of their own

health data, text-based or multimedia-based, that they can bring to any health care provider or facility.

Second is the increasing digitization of health data. With the advent of electronic medical records, automated laboratory machines, and digital radiology equipment, much of what used to be written only on paper or printed in imaging plates are now also available in digital format. These digital files can be transferred from one facility to the next without any degradation of quality. With such data, it is possible to have an examination done in one facility and viewed in another regardless of the second facility's infrastructure.

Third is the increasing availability of Internet connectivity. The Internet allows for the low-cost exchange of data between facilities and between patients and facilities in a seamless manner. It is essentially possible for patient data to be in various places of the Internet and to be consolidated into one comprehensive record in a provider's clinic.

What is in a personal health record? Contrary to common belief, the PHR does not contain all of a patient's health data. Rather it is a subset of data that can give providers a more comprehensive and longitudinal perspective of the patient's care[3]. The ASTM International (formerly American Society for Testing and Materials) has published Standard E 2369 Continuity of Care Record (CCR).

> "The standard provides a core data set of the most relevant administrative, demographic, and clinical information facts about a patient's healthcare, covering one or more healthcare encounters. The CCR data set includes a summary of the patient's health status (e.g., problems, medications, allergies) and basic information about insurance, advance directives, care documentation, and the patient's care plan."[4]

This paper reviews the state-of-the-art in personal health record systems in the Philippines and proposes a framework for its design and implementation.

Method

Literature review of MEDLINE for personal health records will be made and current trends extracted. Owners of local laboratories, radiology facilities, and clinics will be interviewed regarding their existing and planned information infrastructure. Purposive interviews with consumers will also be done. Input from the recent Electronic Health Records Philippines 2006 conference will also be cited.

Results

From the recent Electronic Health Records Philippines 2006 conference[5], several applications were presented which had some components of an electronic health record. The Community Health Information Tracking System (CHITS)[6] is a government health center-based information system designed to manage the administrative and clinical tasks of a local health center. The Integrated Surgical Information System (ISIS)[7] is a hospital-based patient registry that manages data about surgical patients at the Philippine General Hospital. The Blood Bank Information Management Package (BLIMP) manages the donor information system and transfusion services at the UP-PGH Blood Bank. At the Riverside Medical Center in Bacolod, a pharmacy information system called HYSYPTO[8] has been deployed where prescriptions are filled up by the pharmacy right after doctor's orders are scanned on the floor. None of these systems may be called personal health records since all of these are facility-based and do not share any information to the patients. Based on the author's review of literature and of the local environment, there is no end-to-end model right now for personal health records in the Philippines. An end-to-end model allows for the transferring and viewing health data seamlessly and securely from one facility to another with patients serving as the bearers of the data.

In radiology, a few imaging facilities have procured DICOM[9]-compliant equipment which could output digital data. Upon request, these facilities have provided their patients CD-ROMs of their images which patients can view on a personal computer.

Laboratories on the other hand often give out test results in paper printout format. Having no actual system to receive electronic data from laboratories, only a few facilities provide electronic data to their patients in the Philippines. For the few who are able to output electronic data they often deliver results to providers via fax or via email in portable document format (PDF) format. Others allow patients to print out their lab results through a web interface. Presently, there is no laboratory facility that offers electronic data to patients in the raw. The issue foremost in the operators of lab facilities is the integrity of the data once they are in the hands of patients. There is no agreed upon way of assuring that the laboratory data would not be tampered after transferring it to the patient.

As a matter of conventional practice, health facilities, especially providers' clinics, do not give electronic data, in whole or in part, to their patients. Most of the time, the data are in paper format and they comply with a certain template such as clinical abstracts or medical certificates. Rarely will a provider supply a full medical record to a patient. More comprehensive and complex documents such as operative records and surgical techniques can only be obtained from hospitals where the procedures have been performed.

At the policy side, a partnership between the Department of Health, Department of Science and Technology, Philippine Health Insurance Corporation, University of the Philippines Manila, and the Philippine Medical Informatics Society was formalized last October 10th, 2005[10]. The partnership, called the Philippine National Health Information Infrastructure or PNHII, aimed to consolidate the standards for health information in the Philippines. The PNHII focuses on four key areas: capability-building, standards and interoperability, connectivity, and test beds.

The Electronic Commerce Act of 2000 provides much of the policy framework for electronic-based transactions in the Philippines and would include electronic health records.

Discussion

The technological infrastructure to support personal health records seem to be in place already in the Philippines, but the awareness of consumers and openness of providers to the portability of data leaves much to be desired. The issues involved are multi-faceted and multi-stakeholder.

Consumers

Currently, most Filipino patients are not aware that it is their right to have copies of their health data and that they own the data even if they are in paper format and the paper is being managed by the hospitals or clinics. This knowledge is crucial in involving patients/consumers in the care of their own health data. Without an acknowledgement of this right, patients will default the care of their records to health facilities who serve as caretakers of their personal health data. Unless consumers realize that they can manage their own health data, the concept of personal health record systems will not prosper.

Providers and Facilities

The providers and facilities must accept that the patient owns the digital data but that being facilities, they are compelled to retain and manage copies of the data internally. They should also accept that the data must be supplied to the patient when demanded. In effect the provider/facility manages the data, but it is the patient who owns the data within. These concepts must be made clear to all parties for personal health records to be accepted by all involved stakeholders.

However, current local practice puts the control and power over health records to providers and facilities. Shifting the current systems from manual to electronic within a facility is formidable as it is; stiffer resistance is expected for electronic personal health records. Most of the resistance will be encountered from providers who will require additional equipment to view data from personal health records. On the other hand, it is also possible for a consumer-led trend towards personal health records to push the health facilities to invest on infrastructure. It will depend on

generating a critical mass of end users and the establishment of a sustainable ecosystem to make the transition as seamless as possible.

Security

Since personal health records are private, there are substantial security issues that need to be addressed in order to have successful personal health record systems in the country. If stakeholders do not trust the integrity of a personal health record, its utility and value decrease There are four security components that must be addressed by a trustworthy personal health record system. First is the clear identification of the stakeholders (that the system can identify external actors [persons, other systems] before interaction)[11]. All parties involved in the accrual of digital health data must be unambiguously identified – the patient, the facility, the technician, the examining physician, the requesting physician, to name a few. This means a persistent (central or distributed) mechanism for storing authoritative identifiable data must be kept in an accessible place.

A second security component dependent on unambiguous identification is authentication. Authentication is the process by which a previously identified entity is validated to be who the identified person really is. In conventional health record systems, the authenticating process is performed by medical records staff who keep the paper-based records. These personnel are presently in charge of identifying and authenticating their patients correctly.

A third security feature is non-repudiation (extent by which an application makes it impossible for an actor to deny that a transaction has taken place). This follows the principle that disallows an entity that has previously participated in an electronic transaction to refute the transaction. Current advanced devices have already integrated this into their system by using Write Once Read Many (WORM) hard drives. Software based non-repudiation techniques are also available and may be the most practical solutions when data needs to be transferred from one facility to the next.

Authorization refers to the access and user privileges for authenticated users/applications. This security component ascertains whether an entity has the privilege to view the health record. Assigning authority is primarily a social issue but once established, it can be implemented into security systems.

A Use Case Scenario for a Personal Health Record

Here is a proposed scenario for the use of a personal health record:

Upon the request of his family physician, a patient goes to a radiology facility to have his CT scan taken. After the examination, the patient requests for a copy of his CT. Consent and waiver forms are signed and the patient's USB drive is loaded into the facility's personal computer. The patient's digital CT scans are signed by the facility and transferred to the USB drive. Once the data is in the USB drive, any alterations of the file will be detected and any authorized user will be informed of such.

Upon reporting to the provider's clinic, the patient supplies the USB drive to the provider. Using a PNHII supplied software or proprietary viewing software compliant with PNHII specifications, the provider is able to view the patient's CT scans with full view of the digital signature of the facility from where the scans were made. Any alterations in the scans will be detected and the provider informed accordingly.

Electronic documents such as clinical abstracts or medical certificates may also be transferred to the patient's USB drive as long as the security process is followed.

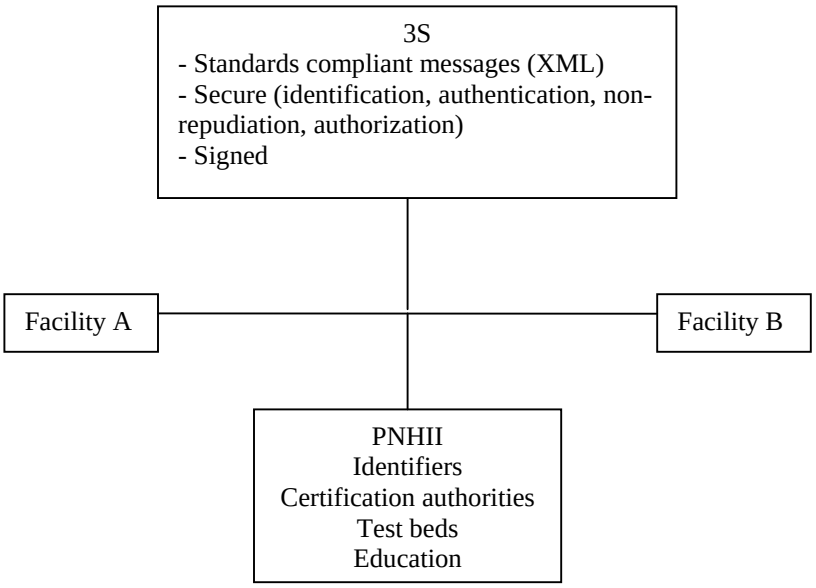
Doubts about file integrity can be resolved by sending the file's fingerprint to a central indexing system or to the originating facility where it is compared to a previous fingerprint in file.

Proposal

Based on current practices and available technology and capacity, the author recommends the following framework for personal health records development in the country. All of the components of the framework will be overseen by the PNHII.

At the semantic level, all messages exchanged between facilities must be consistent across systems. This means the 'standards and interoperability' component of the PNHII must take the lead in determining the vocabulary for the messages as well as the syntax. The messages must comply with the 3S as listed in the figure below.

Figure



For syntax, the eXtensible Markup Language (XML[12]) has become the lingua franca. It is platform-independent and has established itself as a neutral data format that is acceptable to many participating systems.

Once the messages can be constructed in a semantically and syntactically consistent manner, it must be wrapped within a security layer (similar to a secure envelope) prior to the transfer. This is where a certification authority using the public key infrastructure will play a role. The public key infrastructure employs a two-step authentication process which assures that messages exchanged between two trusting entities are protected from alteration. In addition, it also provides a framework for identifying and authenticating the sender and recipients of secure

messages. Stakeholders involved in the transfer of the message (including the patient) will require a public and private key that they will use to sign the data. Since most of the transfers will be from facility (radiology, laboratory or clinic) to patient, these entities are the more important ones who should obtain a key. What is crucial at the facility level is the identification and authentication of the patient and the signing of the unaltered health data (CT, MRI, lab, etc) with the facility's private key and the patient's public key. Identifying and authenticating persons at the facility level may be done on a federated, distributed basis by employing a web of trust.

Central to the adoption of personal health records will be the ease of viewing the data using freely available software. The test beds component of the PNHII will make sure that free reference implementations are available for end users and developers.

Education and awareness campaigns must be undertaken to ensure smooth implementation. The shift from conventional health record systems to personal health records is a giant leap from current reality and is prone to failure unless deliberate attempts to bridge the gap slowly and in measured steps are made. An effective way to overcome resistance from the providers and facilities is to offer the benefits of automation in lowering the cost of operating the clinic or the facility. Focusing on patient empowerment also helps in convincing providers to make the necessary investments.

When patients are more involved in their own health care, including the management of their personal health data, they become active participants in their health care and become more responsible. Providing a platform for personal health records may yet become the foundations for an effective and efficient health care system that is oriented more to the welfare of the client.

The Philippine National Health Information Infrastructure plays a crucial role in making personal health records happen. Personal health record systems may be the impetus that will spur facilities to digitize their operations and allow clients to have electronic copies of their health records.

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