

Health Record Banking A Patient-Centric Solution for Electronic Health Records

Amid current concerns over health care costs and medical errors, there has been growing recognition of the need for health data to be available when and where it is needed to ensure that optimal care is delivered to patients. Health Information Technology (HIT) holds the promise of delivering significant improvements in our overall health care system by addressing this need through electronic means. However, progress toward an effective HIT solution has been slow because of problems including high costs, lack of interoperability of existing systems, and inconsistent stakeholder cooperation. In addition, concerns about patient privacy and the potential for inappropriate access to the data escalate when paper records are converted into more accessible electronic formats.

Health record banking (HRB) represents a realistic and feasible approach to creating an effective HIT system. A health record bank is a trusted third party that securely collects and stores medical information on behalf of consumers, and enables each patient to fully control all access to their own data. HRBs are efficient, cost-effective, and protect individual privacy, and therefore represent a viable mechanism for delivering more complete information for each patient at any point of care. They also ensure stakeholder cooperation since the patients, rather than some new third party entity, are requesting their records from the various healthcare stakeholders.

The Problem

In today's health care environment, the complex web of interactions among providers, institutions, payers, government agencies and a myriad of ancillary services results in medical data existing in multiple forms - including a large percent in paper - and in numerous physical and electronic locations.

The exchange of data among these locations is primarily provider-oriented and driven by individual transactional needs – e.g. sending a claim to an insurer, or sending a laboratory result to a physician. The migration of these transactions from paper-based to electronic, while facilitating administrative information transmission, has not really resulted in speeding the exchange of clinically relevant information, nor has it led to improved care delivery. It has, however, given rise to increased fear of data being accessed or used inappropriately. Well publicized breaches of consumer data have fueled these fears.

While the Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule was intended to address some of these issues, it does not actually assure privacy of patient data, and offers no consumer control of or accountability for disclosures for treatment, payment, or operations (as determined solely by the holder of the data).

Complex technology systems that support multiple providers and organizations, such as Health Information Exchanges (HIEs) and Regional Health Information Organizations (RHIOs) are also driving the availability of patient information when and where needed. Unfortunately, consumers are often given little or no control over who accesses their information in such systems beyond the blunt instrument of a global opt-in or opt-out. If patients' opt out from participating in such efforts they may be denying themselves and their families the benefits such systems can offer. On the other hand, without appropriate safeguards, patients who do participate are at risk of having their data used in ways they might not have wanted and could not have anticipated.

There is considerable evidence that moving to electronic medical information promotes the use of health care data to enhance patient safety, improves the delivery of effective care, and drives down healthcare costs benefiting consumers in the long run. What is needed is a system that

can achieve these goals, while providing consumers with access and control in a way that will instill confidence while giving providers the means to deliver better healthcare.

The Solution - a Health Record Bank

A health record bank or trust is an independent organization that provides a secure, persistent, electronic repository for storing and maintaining an individual's health and medical records that assures that the individual has control over who accesses their information.

There are three critical distinguishing features of a health record bank that make it the model/framework of choice in promoting the storage and use of electronic health information:

- ***Patients control all access to the data***
The patient controls who has access, when they have access and what they can do with it.
- ***The record is patient-centric – not provider or payer-centric.***
The record contains data from multiple sources and providers, as opposed to only containing records for a single provider, care location or payer. Audit and tagging indicate source of the data and contribute to a “trusted source” status and promote clinical credibility by providers.
- ***The record is persistent and portable.***
The patient's record will be persistent and will not “age off” as is typical of most clinical systems in use today. The record will persist through changes in provider or payer, and can be moved from one health record bank to another at the patient's request, without loss of data.

A health record bank can be viewed as analogous to a financial bank with information – not money – as the currency. The consumer deposits money in a financial bank for safekeeping, but the bank only retrieves, stores and disburses it as instructed by the consumer. Similarly, in the HRB the patient authorizes “deposits” of healthcare data/information and “withdrawals” from and to appropriate sources. The bank is responsible as the custodian of the information, but not the owner. The consumer owns and controls the information stored there.

In order to trust the information accessed from an HRB, providers must be assured of its reliability. Records must be tagged with the originating source, and there must be an audit trail of any changes that have occurred. Consumers may be permitted to annotate or add information, but these alterations need to be obvious to clinicians in order for them to rely on the information to help formulate clinical opinions and recommendations.

The HRB model also can offer specific features and options that might be necessary or desirable, such as supporting the concept of an agent who acts on behalf of a consumer, such as parents of minor children.

The “back-office” infrastructure of a health record bank includes secure, redundant storage, a secure network, customer contact centers and document centers. These features are already standard in other sectors of the economy and can all be built with readily available hardware, software, and systems design. It is relatively inexpensive and is already proven reliable and secure using familiar information technology methods.

The HRB approach is also compatible with current community efforts to build effective health information infrastructure, and can address some of the critical issues challenging them today.

Health record banks can achieve sustainability by providing a service that patients, as well as providers, will find valuable. Economic sustainability should be assured if patients and providers find that the service fills a need, as opposed to the economic models promoted thus far for RHIOs and other HIEs, which have not been based on a clear foundation that distributes benefits and costs appropriately. Most importantly, they address patient privacy concerns because they assure that patients have the right to control access to their data.

The health record banking model can provide the same functionality contemplated by HIEs by making more comprehensive patient data from multiple sources available to providers who need it, while truly putting the consumer's needs and rights at the forefront of the effort.

The Time is Now

The convergence of several forces – the emerging consumer empowerment movement, with its focus on the right to privacy; growing awareness of the need to battle soaring medical costs while reducing medical errors; government movement to drive the use of medical information technology combined with the dramatic improvements offered by the use of Health Information Technology - has brought us to a realization that finding a solution is both imperative and possible.

Consumer awareness of their own rights to obtain and control their health data is still an emerging phenomenon, however, the appeal of the health record banking model to consumers is intuitive as it offers them a chance to control and manage access to their information directly. As consumers become more engaged with managing their health records, it should also support them in becoming more active participants in their health care overall.

More importantly, it is highly unlikely that there will soon be a general consensus nationwide about rules to define the specific situations where access to medical information will and will not be allowed. Giving patients control over these decisions allows each person to establish their own customized privacy policy exactly suited to their needs, thereby eliminating the endless policy discussions and debates regarding uniform privacy regulations for everyone.

The needs of the health care system for appropriate access to information are critical and must be met if we are to achieve the improvements in quality and efficiency that are possible through appropriate use of Health Information Technology, but those needs must be addressed in a way that fully recognizes that the patient is at the center and their requirements for privacy deserve as much respect as their needs for care.

Health Record Banking offers a solution that supports the information needs of the health care system (providers and payers) while empowering consumers and protecting their privacy.