Technology Companies are Best Positioned to Offer Health Record Trusts

Shirley Gaw (sgaw@google.com)

Umesh Shankar (ushankar@google.com)

A mistake on your credit report can make it hard to get a loan, but a mistake on your medical chart can kill you. The current health system lacks assurances to patients of data retention and privacy control. We argue that this is due to discrepancies in how health data is reported and consumed and contrast this with how financial credit data is reported and consumed. To address these health system gaps in protection of medical data, we would like to evangelize the implementation of health record trusts. Finally, we argue that Personal Health Records (PHRs) are the closest to offering the main features of health record trusts.

The Fair Credit Reporting Act (FCRA) and the Health Insurance Portability and Accountability Act (HIPAA) deal with similar issues of access and remediation for credit and health data, respectively. In practice, though, consumer use of credit reporting and health reporting are completely different. It is easy to get access to your credit report online, and free to do so once a year. Furthermore, credit reporting is centralized (there are only three major credit bureaus); if you see your report on each of them, you can feel confident you've seen everything, and there are standard ways of adding notes to your file.

By contrast, with health data, the system is completely scattered: it's as if there were tens of thousands of credit bureaus. This lack of centralization makes getting your records tedious, and there's no standardized output. As a consequence of this fragmented and messy system, medical ID theft is on the rise, which can lead to errors in both health record history *and* credit history.

All this has led to calls for *health record trusts*, a term originally coined by David Kendall. Per Kendall, a trust provides the following features:

- Data repository for compiling together all health information about an individual
    - Maintenance of data integrity and documentation of data sources
    - Mechanism for contesting the accuracy of items in the record
    - Data provenance reporting (historical log of who updated which items and how those values changed over time)
- Data transport or data access mechanisms for both health providers and patients
- Privacy controls
    - Specification of consent over how data may or may not be transmitted
    - Reporting of how parts of the record have been distributed, who has access to what parts of the record, and what was the purpose of this access

In addition to centralizing medical information storage, transmission, and privacy control, we would add to this list the requirement of long-term retention of records. Health record trusts should be responsible for replicating the data storage of individual providers so that retention policies or accidents by provider do not create holes in a patient's medical record.

Practically speaking, achieving all the properties above is a difficult challenge---and it is primarily a *technological* challenge. The question then is: who is best positioned to meet this challenge? There are several natural candidates.

- **EMRs** could be expanded to provide this service, and people could choose between different competing options, provided by (say) their HMOs or third parties. We argue that this is unlikely to be workable: EMRs have been built as silos within one administrative domain, and they're not equipped to integrate with *themselves* much less with auxilliary products.
- **Government** IT projects at large scale have a long and robust history of failure. It's generally true that many large IT projects in general fail, and perhaps the main problem with government IT is that it's not really allowed to fail. In private enterprise, if only 3 out of 10 implementations succeed, you at least have 3 working implementations.
- **Technology companies** have experience dealing with large volumes of data from many sources. They have developed open standards for identity management (e.g.,

OpenID) and federated authentication. Perhaps most importantly, they are best-positioned to offer a consumer-focused solution. EMRs' core constituency is care providers, who may not have much to gain from health trusts; after all, they have to move away from a fiefdom model and make their data available on a wide scale to patients, and deal with the issue of corrections.

It's important here to separate the notions of health record trusts and PHRs. A trust is meant to be a complete and authoritative source for an individual's data and a centralized arbitor of giving patient consent for data release and use; a PHR is an application that may use medical data, provide a rich UI on top of it, and integrate it with patient-supplied data such as that from monitoring devices, PDFs of lab reports, and information on compliance with a drug regimen. PHRs lend themselves to being health record trusts more than other systems because the core feature of health record trusts is supporting easy, intuitive import and export; this allows people to make personal backups of their data, check its integrity and accuracy in any manner they wish, and to switch trust providers easily. We need to prevent health trusts from becoming the information silos that EMRs have become, so that patients have choice and portability in who serves as their health trust provider.

What PHRs already do offer, however, is the technological innovation and resources currently available to technology companies. For companies like Google and Microsoft, resource availability is already a sunk cost---they already support large data centers and enterprise services, and, therefore these companies can easily augment this service domain to their existing infrastructure. Likewise, providing access to the data repository is problem already solved in other cloud-computing services---our ability to provide reliable uptime and network access exceeds that of government or academia and many other industrial competitors. Industry already has the infrastructure to support a nationally accessible health record trust.

"Medicare and Medicaid Programs; Electronic Health Record Incentive Program; Proposed Rule", 75 Federal Register 8 (13 January 2010), pp. 1868-1869. (also known as "Meaningful Use" Notice of Proposed Rules Making)

Kendall, David B. "Perspective: Protecting Patient Privacy Through Health Record Trusts." Health Affairs, 28(2), 444-446.