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Putting Health IT on the Path to Success

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The promise of health information technology (HIT) is comprehensive electronic patient records when and where needed, leading to improved quality of care at reduced cost. Unfortunately, physician experience and other available evidence show current efforts leave this promise largely unfulfilled.

Comprehensive records require more than having every physician and hospital use an electronic health record (EHR) system. There must also be an effective, efficient and trustworthy mechanism for health information exchange (HIE) to aggregate each patient's scattered records into a complete whole when needed. This mechanism must also be accurate and reliable, protect patient privacy, and ensure that medical record access is transparent and accountable to patients.

However, when it comes to HIE, often implemented by Regional Health Information Organizations (RHIOs), the lack of progress is particularly discouraging. The President's Council of Advisors on Science and Technology (PCAST) said in December, 2010, that HIE efforts through the states 'will not solve the fundamental need for data to be universally accessed, integrated, and understood while also being protected.' [1] A recent survey of 179 HIEs found only 13 (covering just 3% of hospitals and 0.9% of physician practices) capable of meeting Stage 1 Meaningful Use criteria (which do not guarantee comprehensive records). Of those 13, only 6 were reported to be financially viable. More importantly, none of the HIEs surveyed has the capabilities of a comprehensive system as specified by an expert panel, calling 'into question whether RHIOs in their current form can be self-sustaining and effective.' [2]

Not surprisingly, multiple HIEs have been shut down, e.g., Washington (DC), Kansas, Tennessee, CalRHIO, and CareSpark (Kingsport, TN, once touted as a national leader). According to the Office of the National Coordinator for HIT (ONC), in 32 states over 90% of hospitals have not even exchanged a single patient record. [3] Finally, no patients currently receive their care with guaranteed availability of comprehensive information from all sources.

One consequence of all this is that HIT has yet to decrease healthcare costs measurably – in fact, costs are increasing because of the improved documentation produced by EHRs. HIT cost savings will be realized largely from eliminating duplicate tests and avoiding medical errors – this requires comprehensive records for each patient, not just provider EHRs such as

those implemented within large hospitals or health systems, or in multi-specialty group practices.

Why are the results from HIE efforts so discouraging? Recent funding has been substantial – \$564 million in Federal funds were allocated to states starting in March, 2010, to develop HIEs. The key obstacles have been clearly and repeatedly identified — privacy concerns, lack of stakeholder cooperation, and minimal financial sustainability [4] — but these barriers have yet to be overcome successfully.

The problem is that we are on the wrong path. We are trying to use HIT to replicate existing manual processes for contacting other providers to get patient records instead of creating a single unified record for each patient as we have done for years with paper records within single hospitals and clinics. In other words, we are building institution-centric systems, often leaving patient information where created, and then retrieving and integrating it in real time only when needed.

This seriously flawed approach is:

1. *Complex and expensive.* It requires all EHR systems be online 24/7 responding to queries, as well as implementation of new systems for realtime reconciliation of records from multiple sources. It is extremely difficult to accomplish without a unique patient identifier (which is both politically impractical and a privacy threat). Further, an expensive 24/7 network operations center must constantly monitor and ensure availability of all possible sources of information.
2. *Prone to error and insecurity.* A recent simulation study showed that, in comparison to a central repository, the institution-centric approach requires exponentially more transactions and is exponentially more likely to provide incomplete records due to EHR response failures.[5] The decentralization of the records also allows more security failure points.
3. *Detrimental to provider liability.* Because patients have no opportunity to review or annotate data, the burden of data correctness expands across providers, institutions and the HIE. Integration errors and an inability to propagate corrections to those who already received data further compound lawsuit risks.
4. *Not financially sustainable.* This is a widely acknowledged problem. Financial sustainability should not require providers to underwrite costs (ultimately passed on to patients or insurers).
5. *Unable to protect privacy.* Leaving data at their source makes managing privacy preferences impossibly complex since patients would need to set and maintain permissions separately at each location providing care.
6. *Unable to assure stakeholder cooperation,* since providing records is totally voluntary; requests for them are not from patients, leaving records incomplete and possibly misleading as a result.

7. *Unable to facilitate robust data searching, e.g., for research and public health purposes.* Since each record must be fetched from all sources and integrated every time it is needed, search becomes sequential, which is prohibitively inefficient.

Even with high-speed systems, access to patient information is greatly facilitated by having that information in one place. Consider credit reporting systems; while they are admittedly imperfect, they would be much less effective if they had to query all creditors when a report is needed, and it would be much harder for consumers to review or attempt corrections if records were not in a single location.

The good news is that there is at least one viable alternative that is simpler, scalable, less expensive, more secure, and can provide lifetime records: patient-centric community health record banks (HRBMs). HRBs are community organizations that put patients in charge of a comprehensive copy of all their personal, private health information, including both medical records and additional data that optionally may be added by the patient. The patient explicitly controls who may access which parts of the information in their individual account (for details, see the Architecture and Business Model white papers from the non-profit Health Record Banking Alliance at www.healthbanking.org). When patients seek care, they give permission for their healthcare provider to access some or all of their up-to-date health records. When care is complete, the new records from that visit or hospitalization are securely deposited into the HRB—and made available for the future. This approach solves the problems of privacy (through patient control), stakeholder cooperation (since the patients request their own records, the HIPAA regulations require every stakeholder to provide them electronically if available in that form), and financial sustainability (with revenue from optional apps for patients and research use of the data with permission) and it co-exists with institutions keeping their own local copies of records.

While there have been a few largely unsuccessful commercial efforts using a patientcentric architecture, e.g., Google and Microsoft, their scope has been nationwide, requiring patients manually to authorize each link to a medical information source.[6] In contrast, the community focus of HRBs simplifies patient participation by automatically establishing electronic connections to all relevant medical information sources, resulting in truly comprehensive records (essential for clinical value). Local governance also facilitates the high level of trust necessary to engage a critical mass of patients, and thus makes it worthwhile for physicians to modify their office procedures to incorporate routine access to HRB information.

The idea of health record banks is not new – they have been described and advocated in JAMA and elsewhere.[7,8] What is new is appreciating how health record banks can help us to achieve the HIT vision while most current HIE pursuits page 4 cannot. It is time for physicians to insist that HIT be pursued with realistic, achievable, and measurable goals that will produce readily available, comprehensive electronic records that can actually improve patient care. We need to implement model health record banks and then refine those models to allow them to achieve the sustainability and scalability that have prevented the success of distributed HIEs. Otherwise, HIT may become its own socio-political, legal and economic disease.

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