

Affinity-Driven Health Information Networks

A Practical Alternative to Regional Health Information Networks (RHIOs)

Adrian Gropper, MD

MedCommons Inc.

David C. Kibbe, MD MBA

American Academy of Family Physicians

October 8, 2005

One of the principal goals of a national health information infrastructure or network system (NHIN) is the reduction of unwarranted health care resulting from supplier-induced demand in susceptible regions and communities, contributed to by our current inability to access and assemble information that could lead to more rational and appropriate clinical decisions. It is a matter of policy debate whether fragmentation of key health information in inter- and intra-organizational ‘silos’ is a *root cause* of the notorious variability in US health care costs, or simply an enabler that helps to justify inappropriate and poor quality care. Regardless, there is widespread belief and support among providers of care and those who pay for medical care in this country that improvements and efficiencies in transmission of relevant health care information through the implementation of modern health information technology will lead to lower costs.

How these efficiencies are achieved and at what cost is the subject of this paper. Some researchers estimate that a US national health information network will cost \$156 Billion over the next few years. [1] It is beyond the scope of this paper to analyze all of the assumptions that resulted in such a huge amount, but we suspect that this cost is itself an example of unwarranted variation and supplier-induced demand. Diversity in patient preferences and medical practice approaches may or may not be desirable, but the aggregation of patient information into institutional cartels does not on its face appear a desirable approach, and it is likely to exclude small medical practices from participation due to the high costs of entry. Is adding yet another layer of managed care – this time to control information flows -- to the ones that we already have put in place really the foundation that we want to build our NHIN upon?

This paper proposes replacing the regional network rollout strategy based around large enterprises by starting with the use of a small, well-defined, and accepted set of electronic standards for expressing patient information content, for document transmission, and for locating these in a secure manner. Key among these standards are the ASTM CCR for machine-compatible content, PDF for narrative content, and DICOM for diagnostic imaging content¹. Together with several open Internet standards and protocols, the great majority of relevant patient health information can be made naturally accessible in a timely and secure manner to patients, providers, and others without creating the need to replace most existing computers and networks. Further, we propose piloting and demonstrating the efficacy of this system among national-scale affinity groups such as primary care physicians and subspecialists for the purpose of referral care; among the covered employees of major corporations; or within a provider network of caregivers for the un- and under-insured population in communities. We call this alternative for the establishment of an economically feasible method of health data exchange the Affinity-Driven Health Information Network.

¹ The Continuity of Care Record (CCR) is a structured and coded description of a patient's health summary somewhat analogous to the patient summary screen offered by modern enterprise health records. PDF is a standard for paper-like, human-friendly rendering of electronic documents. DICOM is the standard for exchange of diagnostic medical images.

Separating Practice from Patient Information

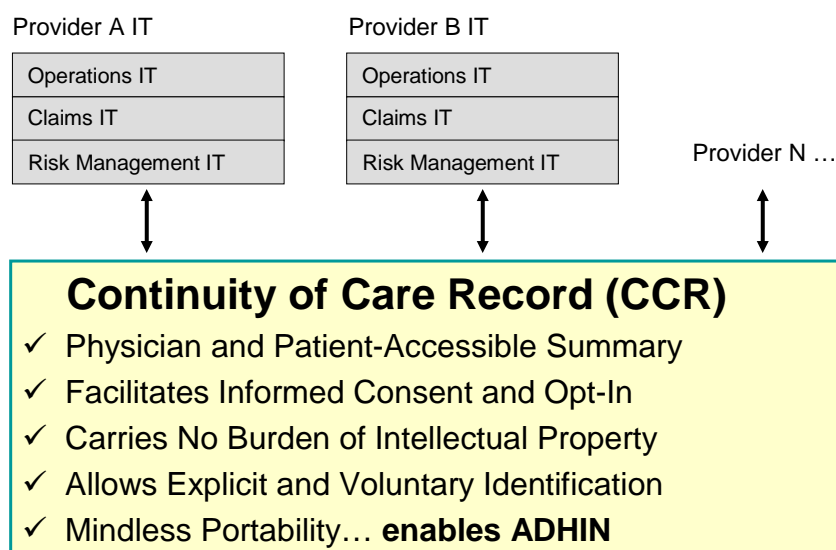


Figure 1 – Interoperability Comes Free when Patient Information is Not Confused with Practice Information

Figure 1 illustrates the banking-inspired approach to private information that underlies Affinity Driven Health Information Networks. Akin to a merchant or employer, each provider, be they a solo physician or a major hospital, hosts information systems that help manage operations. In commerce, we take for granted that our currency is standardized and accessible. In commerce, the currency may be anonymous (cash) or managed on our behalf (an account). Voluntary identifiers such as credit card or bank account numbers make it easy for us to change banks if the institutions that hold our currency in accounts violate our privacy or otherwise lose our trust. The Continuity of Care Record is a currency that supports trust between a provider and a patient. Accountability, interoperability, privacy and informed consent come easily when providers avoid commingling their patient's private health information with their practice management information technology.

Consistent access to information about as many of the patients in the community of interest as possible is the goal of any health information network. Additionally, networks need to be affordable and capable of protecting the privacy of the individuals whose health information is transmitted. Regional health information exchange networks, by definition, give priority to the location of the participant over the clinical application of the information exchange. The affinity-driven approach described in this paper places priority on the interoperability of document content across a specified application-domain and leads to a simple and easily understood network that does not exclude patients cared for in small practices. Our initial choice of document formats spans structured (CCR), narrative (PDF) and image (DICOM) content and makes few assumptions about information technology accessible to the participants. Should this initial set of interoperable document formats prove inadequate for some clinical applications, the addition of other standard documents should be able to follow the architecture already established.

Introduction to Interoperability among Providers

Current solutions to RHIOs tend to presume linkage of patients and physicians to a central entity, often dominated by one or more hospitals, or to assume that the patient or physician is part of a proprietary private network that prescribes a common health information technology through a central agency newly created to fulfill this role within a specific geographic area. We believe this approach to information technology is bound to be expensive, anti-competitive, likely to stifle innovation by locking medical practitioners into a managed IT procurement process of selected “high dollar” vendors, and threatens patient privacy because participation under the policies and practices of the centralized agency may not be voluntary for either patients or physicians. We believe this is the inevitable result of the RHIO movement because it builds technology solutions on top of a largely failed economic and social organization of medical resources, one in which true competition does not exist, rather than permitting new social and economic organizational structures to accompany technological innovation.

In a JAMA commentary², Andy Grove, recently the chairman of Intel Corp., drawing a parallel to e-commerce, highlights the difference between accessible standards and the mainframe with proprietary software era: “The Internet changed all that. Computing became standardized, driven by the volumes of substantially identical personal computers; interconnection standards were defined and implemented everywhere. A virtuous cycle evolved: standards begot large numbers of users, and the increasing numbers of users reinforced the standards. It was easy to become part of an electronic marketplace because it no longer required the installation of proprietary software and equipment.”

What we call here the Affinity-Driven Health Information Network approach is inexpensive and capable of embracing all of the participants in the community of interest regardless of their affiliations with one another or their installed information technologies. It is expressly vendor and technology neutral and requires the use of only two health care-specific IT standards, the ASTM CCR for the structured digital expression and transmission of summary clinical content and DICOM for the digital expression of diagnostic-quality images. All other standards employed are already employed across multiple industries (e.g. banking and publishing), or are Internet standards.

Separating Technology from Policy

Information exchange can move documents either point-to-point or through a centralized registry. Unfortunately, point-to-point transfers alone do not solve the problem of locating a particular document among numerous potential stores of information in an affinity group or community, and point-to-point systems alone do not provide a consistent mechanism for managing access once the document is located.

Therefore, a central document registry is needed to support network-wide location and access control services. Regardless of technology, any registry forces the community to

² Efficiency in the Health Care Industries A View From the Outside; Andrew S. Grove, PhD
JAMA. 2005;294:490-492.

address patient identification, document labeling, and access control policies that go beyond the requirements for point-to-point transfers. Note that a central repository (database) for storage of data files or images is expressly not a requirement of the proposal for a practical network being put forward here.

Given that both interoperable transport and a registry are both needed to create a practical network, should these two components be separate or tightly coupled? The authors believe that separation of systems for document transport (in the point-to-point sense) from systems that control access to private information (in the central registry sense) will lead to benefits in cost, ease-of-use and privacy and will make these network-attached stores of information accessible to patients cared for in all practices within the community of interest, and is therefore preferable to tightly coupled solutions.

By unbundling technology from policy, the Affinity-Driven Health Information Network approach is more likely to preserve early investments in interoperable health information technology. By comparison, the IHE-XDS approach, heavily promoted by enterprise IT vendors, does not allow for point-to-point interoperability and transport without registry involvement. Since registry-dependent interoperability is, by definition, dependent on the policies of the registry, such a system will require either a national-scale policy or additional integration (at significant cost) to support transport across multiple registry policy domains. The Affinity-Driven Health Information Network alternative, by uncoupling transport technology from registry policy, greatly reduces the risk of installing interoperability technology such as CCR and policy-neutral patient-centric transport and archive services such as MedCommons. The market-driven evolution of affinity-driven policies and innovative patient consent (opt-in) systems will, in turn, facilitate national-scale federation of health information networks.

Transport Component

For the transport component, the Affinity-Driven Health Information Network approach proposes XML over HTTP; a minimalist point-to-point approach closely tied to the ASTM CCR standard. The health summary document and patient-centric design of the CCR and its independent control as a standard by physician practice organizations are already demonstrating significant cost, ease-of-use and all around market pull from a traditionally disinterested and skeptical physician-user community. By itself, a CCR transport infrastructure provides easy to understand benefits for secure provider-to-provider and patient-to-provider communications, paperless electronic referrals, and the next generation of CPOE systems with integrated clinical decision support.

Internet transport requires security including the ubiquitous SSL Internet standard and the CCR-mandated XML Encryption standard.

Beyond SSL, encryption key management is required between the source and receiver of the point-to-point transport. In the simplest of cases, SSL alone is sufficient. Another simple case puts the key under direct provider or patient control by allowing the principals to exchange the key by phone or fax. Finally, in the most complex cases, the SAML 2.0 Internet standard is used to control encryption keys as they are checked in or out of various enterprises or registries. This powerful approach is uncontested as the mechanism for single-sign-on authorization between independent and possibly competitive organizations.

Registry Component

The authors define a registry as a well-known address (on the Internet) that maintains directories of documents and the location(s) where each document may be accessed (on the Internet). The registry also maintains and manages the submission, acceptance and access policies for all of the information that it collects. This policy component is critical for both interoperability and privacy reasons since the registry's clients might expect that

document the registry points to is in a useable format and since any query to the registry, when targeted at a particular patient, raises potential privacy issues.

We propose a community-controlled registry that is linked to the transport component by an innovative process that enables both implied (opt-out) and informed (opt-in) consent by the patient. The MedCommons registry integrates a patient-accessible portal by design. This preserves the automation benefits of implied consent as currently assumed in typical HIPAA waivers while adding a mechanism for informed consent or "opt-in" by the patient to make the registry potentially accessible to users who are not covered by HIPAA because they are not part of a patient's direct care team. Transparency and patient access to registry information about them, regardless of whether that information was gathered under implied or informed consent, will speed adoption of Affinity-Driven Health Information Networks and facilitate innovation.

The Affinity-Driven Health Information Network approach to registry management allows for a clear expression of privacy interests among all stakeholders in the registry.

- The CCR standards process is well suited to controlling the labeling of registry data in a nationally uniform and physician-friendly way,
- Individual practitioners can easily understand what data is being indexed by the registry and can more readily de-identify patient data – if necessary - when it is in the familiar CCR form,
- Patients can derive comfort and a measure of added control when a uniform CCR-derived document sanctioned by an organization of national scope is used as the basis for informed consent,
- The affinity group that controls and brands a network can define and enforce registry policy by simply controlling the CCR-based XML schema that defines whether a document will be indexed into the registry database or rejected.

- Finally, the registry service adds value while reducing costs by offering greater transparency and by staying as policy-neutral as possible to allow reuse of its technology investment.

In conclusion, the banking-inspired Affinity-Driven Health Information Network approach gives priority to Internet standards, clearly separates technology choices from policy choices and uses a number of features to enhance the transparency of its operation in order to target what Dr. Brailer has called the “adoption gap” for healthcare information technology to a much greater extent than was heretofore thought possible.