The Engine of Health Information Exchange

Neera Bhansali[a,b] (nbhansal@fiu.edu), Sushil Gupta[a]
[a]Department of Decision Sciences and Information Systems
[b] Biomedical Informatics, Herbert Wertheim College of Medicine
Florida International University
11200 S.W. 8th St, Miami 33199

Abstract
We discuss barriers to implementation of Health Information Exchange (HIE). The focus is on operational aspects of HIE to improve the process of sharing electronic health-related information among various organizations. Various topics include: strategy development, project management, architecture and infrastructure management

Keywords: Health Information Exchange, Governance

Introduction
The healthcare system in United States is complex. Healthcare is delivered to patients in multiple locations via multiple providers who do not share the same electronic medical records. It is fragmented due to non-interoperable and non-integrated clinical data systems. Electronic health records and HIE are perceived as solutions to address the issues caused by fragmented systems, inconsistent communication and incomplete records.

As part of the affordable health care reform, Health information exchanges (HIEs) have been explored as a platform that could facilitate timely sharing of electronic health-related information. This information could be exchanged among organizations to provide timely and effective clinical information at the point of care. The availability of complete clinical data is perceived as a critical component in improving the quality of care and reducing costs (Vest, 2008). Health information exchanges aim to facilitate patients' health information to follow them to diverse provider settings in order to improve the clinical decision processes. It has been suggested that the HIEs would enhance coordination of care, reduce costs, reduce medical errors, improve patient safety and avoid duplication of services (Adler-Milstein et al., 2011).

Patient safety is affected when a complete clinical picture of the patient is not available at the point of care. HIEs could, for example, greatly reduce the number of adverse drug events by finding prior allergies of the patient and improving the accuracy of the allergy list (Kaelber and Bates, 2007). They also have the potential to enhance patient safety through drug-disease information processing by making all patient diagnoses available at the time of drug prescription. HIEs can also provide the ability to detect drug seeking and doctor shopping behaviors (Hincapie et al, 2010). The ability to monitor and potentially control the preceding behaviors can significantly reduce medication abuse and healthcare costs (Walker et al, 2005). HIEs could also address interoperability problems associated with the ability to support longitudinal analyses of

care and public-health needs (Kuperman, 2011). It is also seen as a way to quickly identify affected individuals in the case of a drug recall from the market or healthcare intervention in the likelihood of a pandemic (Vest and Gamm, 2010). The provision of connectivity among providers through HIE would facilitate the coordination of care and reduce duplicate therapy and medical errors (Walker et al., 2005).

HIE benefits have already been perceived by emergency departments' physicians as they see a larger number of patients each day compared to non-emergency department physicians and have to often make their decisions based on incomplete clinical information on the patients. The availability of patient data through health information exchange, at the time of care at the emergency department is perceived as having an important impact on the quality of care and patient safety (Hincapie et al., 2010; Kaelber and Bates, 2007)). It has the potential of providing economic benefits by reducing redundant tests at the emergency department, reducing patient inconvenience, improving patient care and reducing admissions (Frisse and Holmes, 2007).

Regional data sharing initiatives were developed as a response to the ONC (Office of the National Coordinator for Health Information Technology) initiatives and HITECH Act. The HITECH Act did not specify how HIE should be achieved. Organizations and regions aimed to accomplish data sharing through the formation of Regional Health Information Organizations with a goal of enabling exchange of information within a geographical area. The RHIOs collect data using a pull model where clinical data from across providers is pulled and integrated to provide comprehensive information on the patient. As there was no common platform specified, multiple vendor based solutions, that could be used to exchange data, arose. On the other hand, the Direct project initiated by NHIN (National Health Information Network) utilizes a push model which allows providers to send health information securely to another provider. For example, it could be used when a physician sends a referral to a specialist or when the specialist returns the findings to the primary care physician. In the Direct Project, data is transmitted by linking the data from an inbound message to the patient file. The linking can be done electronically using patient identifiers or manually (Kuperman, 2011). However a lack of a sustainable business model has emerged as a main obstacle for the continued growth of RHIOs(Vest and Gamm, 2010). Grant funding was not found to be a viable source of finance and need was felt to develop self-sustaining models.

Challenges

In the last two decades that HIE efforts have been underway, it has been found that the number of unsuccessful HIE efforts far outnumber the successes (Vest and Gamm, 2010). Health information exchanges face challenges on multiple fronts, including a lack of funding, concerns about privacy and security, legal and regulatory issues, technical issues, and organizational concerns.

The rising threat of identity theft through data loss has increased privacy and security concerns in HIEs. HIPAA regulations have been found to be inadequate as a privacy assurance for health information exchange as it does not apply to entities outside healthcare that collect, store and manage information e.g., Google or Microsoft. Also, deidentified data is not covered by HIPAA and raises concerns of third parties being able to reidentify data. Fear of identity theft would promote information withholding behaviors among both patients and providers (McGraw et al., 2009) which would further impede successful health information exchange.

HIEs are faced with technical challenges of combining data from different technology vendors and organizations as well as dealing with complicated administrative issues (Fontaine et al., 2010). Inappropriate organizational workflows and lack of training adds further barriers. Lack of informatics training among business and medical personnel has hampered their ability to develop successful HIE strategies. Lack of financial resources to purchase the software, hardware and network systems to build the infrastructure for HIE, coupled with the lack of technical proficiency to implement and maintain the HIEs between providers present major barriers to HIE implementation (Vest and Gamm, 2010, Blumenthal, 2010).

Patients are important stakeholders in HIE as their consent is required for their medical information to be shared electronically by their physicians and other healthcare providers. Personal Health Records (PHR) and patient portals could enhance patients access to their medical information and lead to enhanced patient-provider communication. PHRs could allow the sharing of patients medical information electronically with their doctors and other healthcare providers through HIE. It could help patients with chronic diseases like diabetes to manage self care and engage actively with their healthcare providers, improving both health quality and safety. However widespread adoption of HIE by patients has been impacted by privacy and security concerns (Donnell et al., 2011). Moreover, physicians question the accuracy and completeness of data collected and maintained solely by the patients (Vest and Gamm, 2010).

Inspite of the positive benefits that would accrue from engaging in HIE, few physicians are found willing to participate in exchanging information. The existing business models require the physicians to pay a considerable fraction of the cost of the infrastructure of the HIE. A survey of physician's attitude towards HIE showed limited willingness to pay for it (Wright et al., 2009). Apart from concerns regarding privacy, there are issues of liability based on decisions made on bad quality data derived from the HIE that deter physician engagement.

Competitive implications of HIE also act as barriers to successful HIE implementation (Vest and Gamm, 2010). Patient data confers a competitive advantage to the participating hospital by tying the patient to the provider. HIE on the other hand requires competing organizations to share their most valuable asset – patients and patient data. It requires exchange of data and cooperation between competing entities which is difficult to achieve. The competitive nature of the health care system provides a disincentive to sharing of information through HIE as it would lose competitive advantage by participating in HIE. Using nationally representative data, Adler-Milstein et al. (2011) found that for-profit hospitals and hospitals with a small market share are less likely to engage in HIE because of their concern about loss of market share. On the other hand they found that hospitals with a dominant market share may perceive participation in HIE as an opportunity. Yet again, responding to market and competitive pressures, organizations may share only a subset of data with a subset of healthcare providers to prevent patient erosion.

Governance

Successful outcomes in IT implementations suggest that project outcomes are dependent on the quality of implementation strategy. Inadequate buy-in by stakeholders, lack of trust in the quality of data and in the secure exchange of data, resistance to change by users, financing of costly network technology, need for process redesign and unclear leadership are some of the common barriers observed between IT implementations and HIE implementation. Applying an over-arching governance framework could address many of these barriers by providing a common

framework and policies and procedures for exchanging information and by providing oversight and accountability measures.

No study has thus far addressed the operational issues of HIE from a governance perspective. Implementing HIEs is a multi-dimensional process that is more than a technical issue. The magnitude of the task is usually significantly greater than expected. It requires the managing of several factors simultaneously (Sicotte and Pare, 2010). The socio, human (Buntin et al., 2011) organizational and legal dimensions of HIE implementation are as important as the technical ones. A governance model is required to develop policies and procedures to provide a clear vision, oversight and coordination over the multiple dimensions of HIE process.

Governance entails the distribution of decision making responsibilities and the definition of the roles that various organizational members would have in HIE. Governance within participating organizations would involve the development of processes for making decisions regarding HIE strategy development, HIE initiative prioritization and budgeting, HIE project management and HIE architecture and infrastructure management. It would involve defining policies and procedures that would govern the organizational use of HIE. HIE organizational responsibilities would involve developing and managing the architectural plan; developing HIE standards, defining procedures to assess sourcing options, managing the portfolio of applications, infrastructure and services and establishing communication mechanisms.

User and stakeholder responsibilities within participating organizations would involve understanding the HIE activities that support their function, ensuring that the goals of HIE initiatives reflect the function's needs, developing specifications for HIE projects, providing feedback to HIE on implementation issues, application enhancements and HIE support, and participating in developing the HIE agenda and priorities within the organization. Management responsibilities within the organization would entail ensuring that the organization has an HIE strategy, balancing the perspectives of users and HIE needs, establishing processes for budgeting, acquiring and implementing applications and infrastructure, ensuring that HIE processes conform to policies and procedures, ensuring that HIE applications and activities conform to relevant regulations and internal controls and encouraging HIE experimentation.

A specific governance board or committee would have to be instituted that would bear responsibility for HIE implementation, initiative specific committees and roles, manage HIE liaison relationships and act as HIE champion. This governing body would be responsible to review and critique HIE technical and organizational strategies, review and critique overall HIE tactical plans and budgets and discuss and provide advice on major HIE issues and challenges.

The questions that remain to be answered are:

- Who should be included in the governing body?
- What powers should be given to the governing body to hold participants accountable?
- Who should establish the rules of data sharing? What should they encompass? How should they be established and enforced?
- What role should the governing body play in financing the HIE?
- Should the governing body be established within a separate entity, such as a not-for-profit?
- Who will hold the governing body accountable for establishing functional health information exchange?

The governance process would help address the predominant barriers to HIE - need for standards, data security, political factors, and disparities in HIE acceptance and use. It would

ensure accountability and enforcement of policies and procedures. Effective governance could facilitate a more coherent vision and inter-organizational business process redesign in HIEs. Support by leadership within and outside the organization could help address conflicting interests regarding data ownership and facilitate HIEs implementation.

Policymakers and stakeholders in HIE should seek to implement comprehensive data security policies that would allow secure transmission of data between organizations thereby increasing confidence in data privacy and security. A governance model addressing privacy issues through privacy policies and regulations would enhance trust in the data exchange through HIEs.

Developing and implementing standard vocabularies for various healthcare data types would facilitate efficient data communication and exchanges between organizations and providers. Developing standards on both the type of data exchanged as well as the breath of information to be exchanged would facilitate better information exchange. Allowing data to be stored and exchanged with metadata would reduce many of the errors associating data to the same patient, between organizations. Instituting processes for clearly defining relationships between different owners of data would facilitate better data exchange processes. Instituting processes for formal patient consent for data exchange, data access and data use policies (Frisse et al., 2011) would further help alleviate data security and privacy related issues.

Users and physician attitude towards adopting electronic health record and HIEs is important to its success. Soliciting the views and participation by all stakeholders early in the process of implementing HIEs would lead to greater buy-in and easier adoption down the road. Design of the HIE system based on stakeholders feedback and providing adequate user support during implementation are important considerations. Participation by all stakeholders early in the process help in reducing political barriers and provide deeper understanding of information constraints and information need and use among the different stakeholders of healthcare. Managing stakeholder expectations also helps in minimizing conflicts and facilitate better risk management. Providing incentives to stakeholders would further assure their participation. Although an HIE could financially benefit the payers substantially, yet they are absent from most HIE initiatives (Fontaine, 2010; Adler-Milstein et al., 2011).

Coordination of health IT standards is required for uniform implementation and integration of administrative, financial and clinical data transactions. Health data exchanged over HIE would include patient electronic record data, medication data, laboratory data and patient consents. Several base standards for data types already exist such as HL7, a healthcare informatics interoperability standards, PACS (Picture Archive and Communication System)standard within the field of radiology, LOINC (Logical Observation Identifiers Names and Codes) standard for identifying laboratory observation, SNOMED CT (Systematized Nomenclature Of Medicine Clinical Terms),that could be referenced. Standardization and integration of clinical and administrative data would facilitate communication and lead to greater efficiencies. Through standardized operating rules, it would allow for more seamless exchange of information leading to a reduction in costs and efforts for patients, providers, and payers (Buntin et al., 2010)

Legislative mandates would be a powerful motivator to institute governance for successful health information exchange. State and federal policymakers would have to address the barriers to HIE either by instituting penalties or stronger incentives would be needed to overcome concerns of competition and loss of market share, to successfully engage organizations in health information exchange.

Conclusion

Health information exchange (HIE) is the process of sharing electronic health-related information among organizations according to nationally recognized standards. The HITECH Act and meaningful use aim to promote the building of a health Information infrastructure in which patient data is exchanged across a national health information exchange. State and regional HIE leaders face an uphill journey to health data interoperability between disparate healthcare information systems. This paper explores the role of governance in navigating the barriers to Health Information Exchange (HIE). It discusses the governance processes and structure, organizational and stakeholder responsibilities, governance issues that need to be addressed and applicable lessons learnt from effective application of IT.

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