



State Level Health Information Exchange

Final Report Part II: Coordinating Policies That Impact Access, Use, and Control of Health Information Executive Summary

Prepared for:
Department of
Health and
Human Services,
Office of the
National
Coordinator for
Health Information
Technology (ONC)

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MX1337



Contract Number:
HHSP23320074100EC

March 10, 2008

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Executive Summary

Introduction

The State-Level Health Information Exchange (HIE) Consensus Project (Project) began in 2006 under a contract from the Office of the National Coordinator for Health Information Technology (ONC) with the Foundation of Research and Education (FORE) of the American Health Information Management Association (AHIMA). The Project is focused on bringing forward relevant field research, guiding ongoing HIE development among states, informing federal-level HIE strategies, and helping to align multilevel efforts to establish a nationwide health information network (NHIN). It is accomplishing this goal through dissemination of field research and guidance materials and broad stakeholder dialogue. A Steering Committee composed of leaders from a mix of state-level HIE entities plays a pivotal role to guide and contribute to research and analysis and to formulate Project recommendations for advancing HIE development.

Project activities carried out between March 2006 and January 2007 produced a series of reports and guidance for emerging state-level HIE initiatives and federal HIE strategies.

- *Development of State Level Health Information Exchange Initiatives Final Report, September 1, 2006.* Outlines the distinct value and characteristics of state-level HIE development and includes an initial set of recommendations for state, federal and private-sector activities to advance state-level HIE initiatives.
- *Development of State Level Health Information Exchange Initiatives Final Report: Extension Tasks, January 2007.* Presents research findings and recommendations related to four areas: the relationship between state-level HIEs and federal activities, analysis of HIE projects that have achieved financial sustainability, roles and influence of public payers on state-level HIE activities, and roles of state-level HIEs in quality improvement and reporting.
- *State Level Health Information Exchange Initiative Development Workbook: A Guide to Key Issues, Options and Strategies, February 2007.* Established a resource for state-level HIEs including practical policy and practice guidance for establishing state-level HIE governance, structure, operations, finance, and HIE policies. Provides profiles of the state-level initiatives represented on the Project's Steering Committee.

All of the Project's reports and the Workbook are publicly available at www.staterhio.org.

The Project embarked on its second phase of work in March 2007 to continue examination and analysis of evolving state-level HIE issues. Activities included continued field research and analysis into dimensions of state-level HIE, facilitating stakeholder input, and developing options for structuring state-level HIE as part of a nationwide network, including defined HIE-related roles and accountabilities.

Research was organized into three tasks.

1. To further examine the evolving functions and governance structures of state-level HIE initiatives

2. To identify sustainability considerations related to these HIE roles, services, and business models
3. To identify the challenges in crafting consistent data access, use, and control policies and practices across HIEs

The Final Report from the 2007 Project is divided into two separate documents. Part I of the Final Report addresses Tasks 1 and 2 and includes findings related to state-level HIE governance and sustainability considerations, as well as recommendations related to state- and federal-level HIE strategies.

This Part II of the Final Report represents a synthesis of current research findings, analysis, and recommendations related to the Project's Task 3 research. It examines the challenges faced by HIE organizations in coordinating implementation of consistent policies and practices pertaining to the access, use, and control of health information.

Background and Methodology

A number of local, state-level and HIE entities participating as contractors in the NHIN are entering the trial implementation stage. Anticipating their challenges and identifying practical solutions will increase operational efficiency and contribute to a likelihood of success in establishing sustainable data exchange. Some of the most difficult challenges facing HIEs relate to structuring data access, use, and control policies and procedures, particularly in the following six areas: access management, authentication, subject and user identity arbitration, management of consumer choices to not participate in the network, availability of access and disclosure information regarding a consumer's personal health record (PHR) and HIE data, and routing of consumer requests to correct data.

These aspects of data exchange generate numerous and complex issues that are compounded by the number of factors that affect them. These include health policy; federal and state laws, rules, and regulations; technical standards; HIE architecture and operational policies and procedures; business practices and agreements; business models; and presence of a governance structure, such as that provided by a state-level HIE organization, that effectively coordinates and oversees these factors.

Previous analyses and existing projects, such as the Connecting for Health Common Framework, NHIN prototypes, the Health Information Security and Privacy Collaborative (HISPC), and the Health Information Technology Standards Panel (HITSP), have already identified a number of access, use, and control issues that may hinder the exchange of health information. The intent of this research and analysis is to add value to previous work and identify the obstacles to successful data exchange or threats to the business models of HIE entities caused by the *interaction* among the six aforementioned areas of access, use, and control and the multiple factors that affect them.

A multidimensional analysis of these factors at the operational level can produce specific and detailed findings, and, more importantly, indicate how operational policies and procedures, data use and reciprocal support agreements, service level agreements, privacy laws, and technical standards may need to be constructed or modified. The practical solutions that these implications might suggest can then be implemented proactively by HIEs, and, thus, help to avoid some of the pitfalls identified in this report. This premise is the basis for, and value of, this project.

The specific goals and objectives of this project are to:

- Examine the current landscape of HIE access, use, and control policies and practices at the national, state, and local levels
- Identify access, use, and control issues specifically related to state-level HIE roles, functions, policies, and practices
- Identify specific points in the HIE process flow where any of the six target areas of access, use, and control are affected by the interaction of multiple factors and describe how HIE may be hindered by one or more of these effects
- Identify the implications for access, use, and control policies and practices, as well as for health policy; federal and state laws, rules, and regulations; technical standards; HIE architecture, policies, and procedures; business agreements, practices, and models; and state-level HIE roles when access, use, and control are affected by these factors
- Identify the potential threats to HIE business models when access, use, and control are affected by these factors
- Develop appropriate high-level and detailed recommendations
- Develop a set of preliminary questions and a methodology that can be used in future studies as a framework for analyzing the complexity of the issues

Given the number and complexity of the issues surrounding the six target areas of access, use, and control, a methodology was developed to analyze a realistic HIE scenario, mining it to address the above goals and objectives. Key components of the methodology include: (1) development of a composite scenario that embodies the data management issues identified as priorities for this analysis; (2) a preliminary set of mining questions that could be used to explore the interaction of various factors and their effects on the six targeted areas of access, use, and control; and (3) a structured walk-through of the scenario to conduct a multidimensional analysis. The scenario that was composed involved the need to access registration summary information and medication history data, as well as laboratory results—use cases deemed to be immediately relevant to state-level HIE and NHIN trial implementers.

Key Findings and Observations

Application of this methodology produced a number of complex findings, implications, and recommendations. These were organized according to the four major stages of the scenario: (1) preliminary steps related to requesting information (registration summary and medication history data, as well as laboratory results); (2) requesting and receiving registration summary and medication history data; (3) requesting and receiving laboratory results; and (4) follow-up steps after requesting and receiving the information including patients verifying that the information imported into their PHRs is correct and patients requesting corrections to data.

Example 1 revealed how master patient index (MPI) contamination can spuriously populate HIE systems with inaccurate data and how responding HIEs can send inadvertently erroneous data to requesting HIEs as a result. A number of implications arose, including whether there should be a mechanism for the requesting HIE to notify the responding HIE that it received erroneous data and whether there is any responsibility on the part of responding HIE to take action to improve the data quality of the MPI after receiving such notification. Lastly, it was pointed out that improving the MPI's data quality on the front end could avoid consumer requests to correct data on the back end, saving HIEs time and resources to make such corrections.

Example 2 dealt with the issue of a consumer choosing not to participate in the network. This example pointed out how confusion will occur because such a choice may return no health information to the requesting HIE. The critical aspect is whether an explanation should accompany the message explaining why there is no health information to return. Without an accompanying explanation, the requesting HIE may not know whether there is no actual health information to return; there is no health information to return because the consumer has elected not to participate in the network, but health information truly exists and can be accessed directly from the source care delivery organization (CDO); or there is a state law preventing the responding HIE from sending the requested health information. Interestingly, Example 2 highlighted how differences in HIE architecture would cause state-level HIEs and local HIEs to address the issues differently.

Example 3 described how consent directives implemented across multiple CDOs, local HIEs, and state-level HIEs can potentially cause conflicts among patient consents. The example discussed ways in which such conflicts can be reconciled. Lastly, the example pointed out how minimizing conflicts in consent directives on the front end can avoid the time and resources to correct them on the back end, thereby enhancing provider and consumer perceptions of the quality of HIE operations.

A number of conclusions and general principles can be gleaned from the results of these three examples, including the following: (1) the methodology was proven to be useful and could be implemented in the field, as well as serving as a framework for future studies of this nature; (2) tighter front-end controls may save effort on back-end processes; and (3) the analysis of the findings, implications, and recommendations generates a discussion that is equally as valuable as the results themselves and can spur multiple stakeholders in the field to find practical solutions appropriate for them.

Given the usefulness of the methodology and value of the findings, the following actions are recommended:

- The findings, implications, and recommendations and the methodology should be distributed to the NHIN contractors so that they can factor them into their trial implementations.
- There is much synergy between the state-level HIE and the NHIN trial implementers. There is an opportunity to take advantage of the leverage that can be obtained through collaborative efforts. The state-level HIEs and the NHIN trial implementers should plan on ways to collaborate with each other.
- Given the time and resource constraints of this project, many of the ways in which the factors interacted with the six areas of access, use, and control were not analyzed. Further funding should be provided to continue this effort.