The State-Level Health Information Exchange Consensus Project

HIE Policies and Practices: Developing Options and Implementation Guidance To Foster Consistency

Interim Report

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INTRODUCTION

In March of 2008, the State-level Health Information Exchange (HIE) Consensus Project (Project) produced a report entitled *State Level Health Information Exchange: Coordinating Policies that Impact the Access, Use, and Control of Health Information* (www.staterhio.org). Under the terms of the Project's extended scope of work through January 2009, the Project is

continuing these research and consensus-building activities related to state-level HIE policies and procedures. These efforts focus on identifying options, producing recommendations and developing implementation guidance that will foster greater standardization in HIE policies and procedures and contribute to the efficiency and effectiveness of HIE implementation.

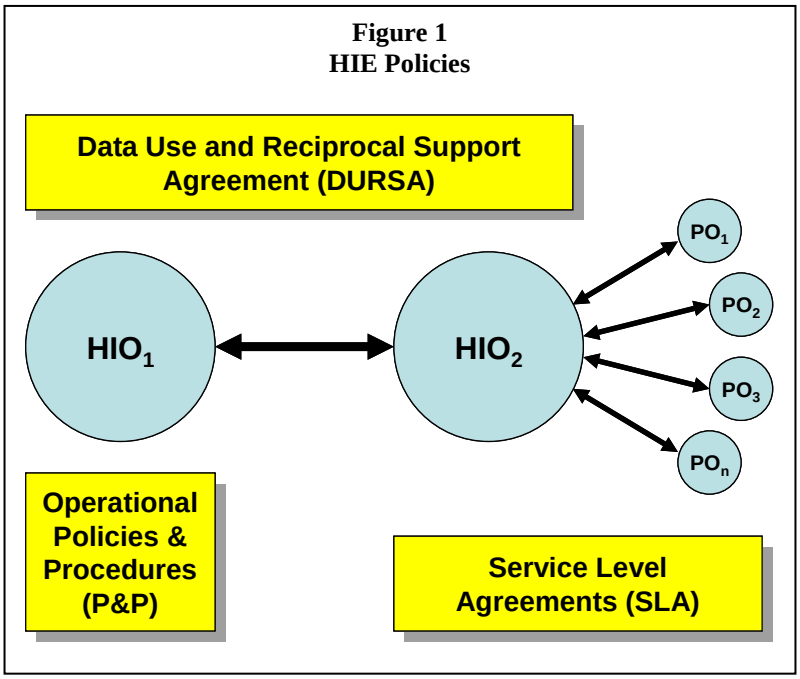
This interim report provides an overview of the research task including background, objectives and approach, methodology, preliminary observations and ongoing activities.

Background

A key component for effective HIE is the establishment of policies and procedures that structure the parameters for data sharing between any health information organization (HIO)[1] and its participating data sharing partners. These data sharing policies and procedures, collectively referred to hereafter as HIE policies (see Figure 1) include:

- The business agreement between HIO to HIO (through the DURSA)
- The operational policies and procedures within the HIO (P&Ps)
- The service level agreement between the HIO and its participating organizations (SLA)

Figure 1
HIE Policies



Establishing and overseeing these HIE policies and practices are key governance functions of state-level HIE entities and other HIOs, including those participating as part of NHIN implementation.

Previous Project research examined HIE policy coordination and issues relevant to state-level HIE, considering the intersection of public policy, laws, and technical standards with developing HIE efforts (technical architectures; policies, procedures, and practices; business models; and organizational roles).

[1] Consistent with "Defining Key Health Information Technology Terms," a National Alliance for Healthcare Information Technology report to the Office of the National Coordinator for Health Information Technology, published April 28, 2008, the term HIO (noun form) is referred to organizational entities that conduct HIE (verb form).

Key findings included:

- Inconsistencies among various HIE policies and procedures, including data use and reciprocal support agreements operational policies and procedures, and service level agreements create gaps which could hinder HIE, generate additional work for HIOs, and raise questions among providers and consumers about the credibility and value of HIE.
- Fostering greater standardization among HIE policies and procedures will contribute to efficient and effective HIE implementation. Coordinated review of current HIE policies in use and under development can generate recommendations for where model HIE policy provisions and language, technical standards, aspects of public policy, and other practical solutions can address gaps in policies and strengthen efforts to implement data sharing procedures across various HIE implementation projects.

Research Purpose and Approach

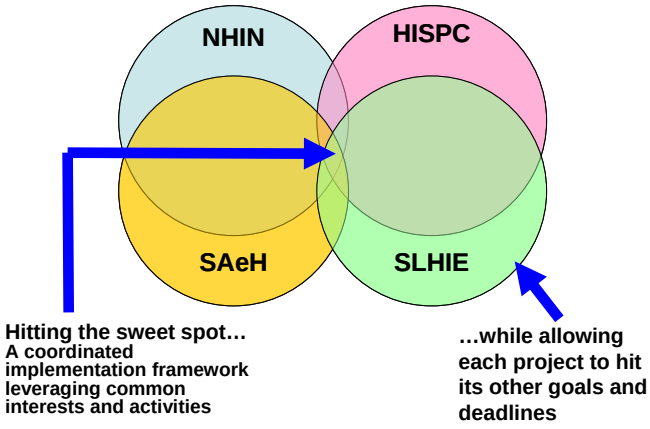
The objectives for these current Project research activities include:

1. Develop recommendations for strengthening HIE policies to increase their effectiveness and applicability. These recommendations may include:
    - specific model language that can be included in HIE policies,
    - public policy actions that may be needed to aid effective implementation of HIE policies and procedures,
    - additions or revisions to technical standards when indicated from the gap analysis,
    - other practical solutions as needed.
2. Develop and disseminate useful tools and implementation guidance that foster application of standardized approaches to HIE policies and practices and support state-level HIE and other HIE implementation efforts to advance production data exchange.

The approach to meeting these objectives is designed to build upon ongoing HIE policy development efforts (e.g. by HIOs and HIE-related projects e.g. Health Information Security and Privacy Collaborative (HISPC), National Health Information Network (NHIN) implementation, State Alliance for eHealth (SAeH)) and contribute a useful, consistent methodology and analytic framework that can identify core elements present and/or needed to accommodate technical environments, ensure adequate privacy and security, and promote data sharing by fostering credibility among stakeholders.

Given the pressing implementation priorities of HIOs and other HIE implementation projects, the Project's research and analysis is focused on key priorities for HIE policy development from among several recognized domains of interoperability. Several potential areas of interest—the "Sweet Spots" (see Figure 2)—that are both high in priority and potentially useful to the NHIN, HISPC, SLHIE, and SAeH projects were identified by the Project Staff. A short list of these priorities for analysis is being vetted by Office of the National Coordinator (ONC) staff and mutually agreed upon as priorities for the Project's current research focus.

Figure 2
HIE Policy Priorities
Areas of Common Interests (The "Sweet Spot")



This prioritized approach leverages and addressed common interests and timeframes across the work of ongoing federally sponsored projects and expands the participation and benefits to local and state-level HIE implementation efforts.

Over the course of the Project's research and analysis, recommendations will be produced and vetted among stakeholders to facilitate points of consensus regarding the content of a key set of HIE policies that can serve as models, or frameworks for HIOs and HIEs looking to implement data exchange. The research team is compiling and synthesizing existing resources, conducting analysis and iteratively sharing the analysis for reaction and input to facilitate consensus, issues of debate or the need for further analysis will continue to be identified and discussed among key informants.

At the conclusion of the analytic activities, the Project Steering Committee and Leadership Forum, other HIE implementation projects and stakeholders will examine the results of this research task and the set of recommendations produced and consider the implications for local, state and national level governance and policy coordination. The State-level HIE Consensus Project will focus on providing information dissemination and useful tools and guidance to emerging state-level HIEs.

Research Team
In conjunction with Project staff, the research team responsibilities include:

- ❑ Review existing resources and materials
- ❑ Conduct gap analysis research
- ❑ Gather and synthesize input
- ❑ Documentation:
  - HIE policy issues
  - Recommendations
  - Final report, progress reports, and presentations related to the Project's research task and activities

The Project's research is led by a team of health information management experts from the AHIMA staff including Donald Mon, Vice President, Practice Leadership, and Harry Rhodes and Lydia Washington, Directors.

Collaborative liaisons helping to facilitating coordination across projects for information sharing and input across the NHIN, HISPC and State Alliance projects including Linda Dimitropoulis, RTI International; HISPC project Steering Committee; and ONC staff Laura Conn, Steve Posnack, Chris Muir, Betsy Ranslow.

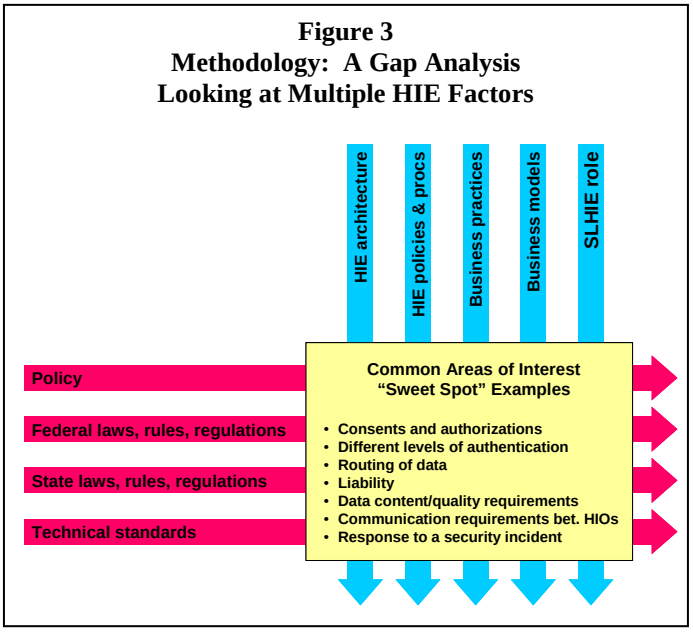
METHODOLOGY

The research team developed and will apply a two part methodology for HIE policy analysis and development of recommendations.

Part I: HIE Policy Analysis

1. Synthesize relevant materials and collect input regarding HIE implementation timelines to identify common areas of interest and priorities for HIE policy analysis e.g. 3-6 specific components of HIE policies to be analyzed. (See *Attachment* for list of potential priority areas).
2. Review reference documents and requirements impacting HIE policy development (see Figure 3) including existing reports, inventories of laws, various forms (e.g., consent/authorization)
3. Conduct a structured walk through of health information exchange between HIOs using select scenario(s) (see SLHIE Final Report Part II, FORE, 2008) to conduct a gap analysis, examining multiple factors one variable at a time. Elements of the multi-factor approach (see Figure 3) include:

Figure 3
Methodology: A Gap Analysis
Looking at Multiple HIE Factors



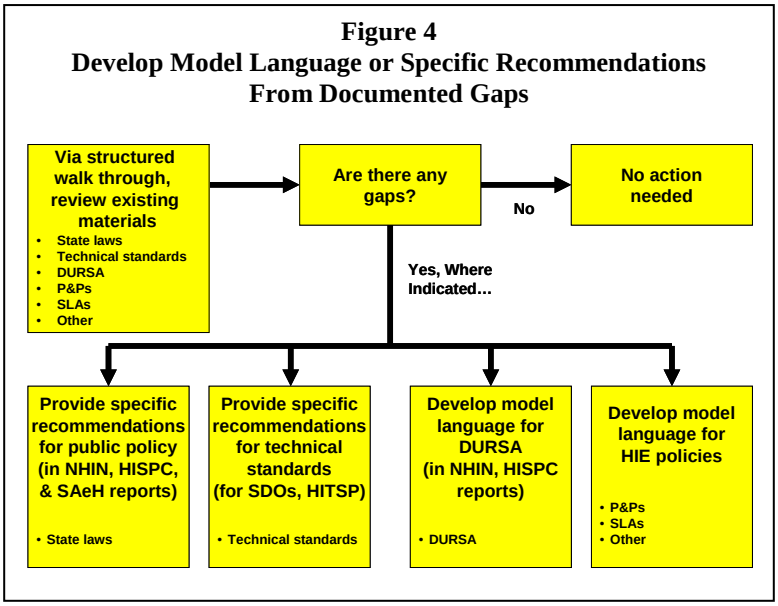
a. The gap analysis begins by focusing on a priority issue (from yellow box in Figure 3)

b. The walk through of a HIO to HIO transaction is started and continues until the first key factor (one of the red rows or blue columns in Figure 3) is identified as having an impact on HIE policy, public policy, or a technical standard or vice versa.
c. The impact or gap is then documented (see next step).
d. The gap analysis continues by determining whether a second factor impacts HIE policy, public policy, or technical standard (simultaneous effects) and vice versa, documenting once again the identified effects and continuing as an iterative process continues until it appears that there are no more factors involved in that step.
e. When all effects have been exhausted at that step of the walk through, the analysis moves on to the next step of the HIO to HIO transaction, and the iterative process repeats for each step until the entire HIO to HIO transaction is complete.

Part II: Developing Recommendations

1. Based on results of policy analysis as above, identify gaps and potential options for model language for HIE policy and/or specific recommendations for public policy and technical standards (see Figure 4)

Figure 4
Develop Model Language or Specific Recommendations From Documented Gaps



2. Provide results of analysis to NHIN, HISPC, and SAeH projects for review and input.
3. In conjunction with feedback from ONC and other projects, a set of potential recommendations can be formulated for further consideration by the Project and other stakeholders. How and by whom these will be developed (e.g. a HISPC collaborative, NHIN participants, etc) will depend upon the outcomes of the particular analysis and the nature of issues identified for further action.

ACTIVITY TO DATE AND FINDINGS

The beginning phase of this research activity has focused on compilation of relevant materials, soliciting input from ONC and other projects and stakeholders regarding priorities for HIE policy analysis, and conducting initial background analysis of key source documents. The timing for these activities has been impacted by the need to compile resources and organize priorities,

timelines and approaches for information sharing and collaboration to ensure effective coordination across informants and stakeholders.

Two priority areas were selected for beginning initial analysis:

- authentication and audit, and
- consent and disclosure.

These particular dimensions of HIE policy represent important components of NHIN core requirements, are a focus of efforts by four of the seven multi-state collaboratives under the auspices of the HISPC project (Adoption of Standard Policies, Consent 1 Data Elements, Consent 2 Policy Options, and Harmonizing State Law collaborative work groups) and are of concern in state-level HIE implementation.

The research team has reviewed the following materials:

- The April, 2008 version of DURSA from the NHIN project
- The Update to the October 9, 2007 Report on State Laws Related to Electronic Health Records and Electronic Health Information Exchange from the HISPC Harmonizing State Law Work Collaborative
- The Oklahoma Standard Authorization Form and the Minnesota Standard Consent Form
- The IHE Basic Patient Privacy Consents (BPPC) Profile
- The HITSP Transaction Package (TP 30) on consent directives

Beginning with a focus on consent and authorization, the initial gap analysis in progress targets Minnesota and Oklahoma and examines the scenario of exchange of health information between two HIOs.

Preliminary Observations

Through this case study, issues and observations can be noted. These illustrate the type of findings generated through this analytic approach, and what will potentially be subject to further consideration by key informants and stakeholders in later stages of the work to develop appropriate HIE policy recommendations.

Walking through a data exchange scenario between two HIOs based in different states applying the methodology illustrated in Figure 3, the following factors come into play as the HIE transaction proceeds to a point requiring consent.

- **State law, provider practices and interstate HIE.** Oklahoma has passed a law wherein providers who use the approved state authorization form will be immune from liability. Ironically, while OK's law may be an incentive for intrastate HIE, it may actually slow down interstate HIE.
  - If patient and the provider are both in OK, a patient signs the OK state authorization form to release information to the provider in MN. Patient uses the OK state authorization form as per usual practice by the provider, motivated by immunity from liability. The MN provider may reject the OK authorization because of differences between the OK and MN requirements for consent/authorization. This type of thing occurs frequently today.
  - If the patient and provider are both in MN and requesting information about previous health care from an OK provider, the MN patient executes and MN provider sends a

MN consent form with a request for release of information to the OK provider. However, the MN state consent form does not grant immunity to the OK provider. Consequently, the OK provider may ask the MN provider to complete the OK state authorization form. In this situation, the process has slowed down and the issues of the differences in state consent requirements arise once again.

- Addressing implications for a standardized approach to HIE policy involves multiple factors including public policy at a state and potentially national level. Two HISPC collaboratives (Consent 2 Policy Options, Harmonizing State Law) are currently addressing these types of issues. The NHIN DURSA is intended to structure data sharing across state boundaries, thus also has need to consider the outputs of this analysis to assess the current provisions and needs required to support production data exchange. The results of this analysis, once completed, will be shared with the HISPC and NHIN participants for validation and development of recommendations taking these results into account. Similarly, any ongoing outputs from the collaboratives and NHIN should be assessed against this analysis to foster development of the most effective models and policy solutions for multi-state HIE policies.

- **Consistent and accurate health information management (HIM) privacy terms and practices reflected in HIE policies.** It is interesting to note that MN calls their document a statewide *consent* form, while OK calls theirs a statewide *authorization* form. While the two concepts are very similar, there is a fine difference between them. The research team is currently reviewing the forms to determine if the forms truly reflect that difference (one is a consent, one is an authorization), or if the terms are simply used interchangeably and there is no harm except for the correct use of the terms. This is not a major issue, but one that will nonetheless be brought forward for hopefully quick resolution.

- **Synergy between public policy, HIE policies and practices.** Of greater concern is whether or not the various statewide consent/authorization forms contain the same attributes (i.e., terms for revocation and expiration, sections of the record to be released, etc.). Lack of harmonization at the attribute level may be enough to trigger the provider in one state to reject another state's consent/authorization. Input from the HISPC Consent 1 Data Elements collaborative work in progress will be factored into this ongoing analysis and the results shared for validation, additional input and development of HIE policy options.

- **Technical standards interacting with HIE policy.** The aforementioned statewide consent/authorization forms are currently paper based. For HIE to occur in an automated fashion, consents could be contained in the HITSP consent directive. Currently, the research team is analyzing whether the attributes of these forms can be contained in consent directives. If not, an HIO would not be able to implement its statewide consent electronically (worst case), thus retarding the HIE process. A less than worst case scenario is one where a statewide consent can be implemented via the consent directive, but the latter contains too much optionality in the standard for all states to implement the consent directive seamlessly. Pending validation of the findings and discussion with the HISPC Consent 1 Data Elements and Consent 2 Policy Options collaboratives, it may result in recommendations for revisions to technical standards, as well as in the attributes for statewide consent.

- **Two public policy issues interacting with each other.** Assuming that the above issues are resolved, then as per the methodology, the walk through would proceed to the next step in the HIE process. At this point, the authentication of the requesting provider(s) must be considered. The project staff will shortly begin the work to delve into analysis of the implications of the interaction of these two public policy issues at the granular level, again sharing key points of analysis, issues, and questions with appropriate informants and stakeholders across relevant HIE projects.

- **Data quality**. An article in the December 2007 version of the DURSA warranted that the data sent by the responding HIO is accurate, even though, as found in previous Project HIE policy analysis, the HIO might not know whether the data were accurate or not. The April 2008 version of the DURSA has rectified the situation. The article has been revised to state that the HIO verifies and confirms that the data is an accurate reproduction of the data in its Systems. Thus, though the data may still be erroneous in its System, the HIO has nonetheless sent an accurate reproduction of it. This may be suitable as business agreement for liability purposes, but a SLA between the HIO and its participating organizations to improve data quality will still be required. Otherwise, as reported in the Project's March 2008 Final Report Part II, the erroneous data may still result in a patient's request to correct data throughout the myriad HIOs to which the data has been sent.

WORK IN PROGRESS AND NEXT STEPS

Work is continuing to complete analysis related to consent/authorization and authentication and audit, and to verify other priorities for the scope of this research activity based on feedback related to the NHIN implementation timeline and the progress being made through the HISPC collaboratives. As analysis is completed and disseminated, appropriate strategies for developing recommendations and options for next steps will be formulated in conjunction with the Project Steering Committee and with input and collaboration across relevant projects.

REFERENCES

FORE (Foundation of Research and Education of AHIMA). (2008). State Level Health Information Exchange: Coordinating Policies that Impact the Access, Use and Control of Health Information Final Report Part II. Prepared for: The Department of Health and Human Service, Office of the National Coordinator for Health Information Technology. Contract Number: HHSP23320074100EC. www.staterhio.org

Mon, Donald T. (2008). Developing a Consensus for Model Health Information Exchange Policies. Presented at the Joint NHIN-HISPC-SLHIE Forum, May 1, 2008, Dallas, TX.

ATTACHMENT

POTENTIAL TARGETS FOR HIE POLICY ANALYSIS AND DEVELOPMENT

- Authentication and audit
- Consent and disclosure data requirements
  - Managing multiple consent directives
  - "Authorization" vs. "Consent"
  - Rules (state laws) related to surrogate permissions (e.g. role of Power of Attorney, minors, incarceration, foster care, etc.)
  - Liability for re-disclosures: How is consent interpreted? Does it apply to only one custodian or all to whom the information passes?
  - How is revocation of consent communicated to those to whom information has already passed?
- Communication requirements
  - Supplying a reason for "no return of health information"
  - How are corrections and amendments handled for known inaccurate or incomplete information that has already been disseminated?
- Data content/quality requirements
  - Summary Record
  - Standards for accurate patient identification
  - Handling inconsistencies of information between provider organizations
  - What to do when contaminated data is discovered
- Policies related to uses of information in or available through the exchange
  - Reporting to public and private payers
  - Public health and population studies
  - Law enforcement and legal uses, individual and aggregate data level
  - Research uses
  - Commercial uses (e.g. sustainability models - brokering data as revenue)
  - Linking data from various sources, impact on privacy (e.g. medication data to assess medication use/abuse; previous medical history/occupational or other injuries; insurance and pre-existing conditions)
  - Data retention (e.g. clinical data in a central repository, timeframe per type of data)
- Response to a security incident
  - Mandatory/non-mandatory notification of breaches
  - Standards for audit logs and auditing policies and procedures
  - What to do when a case of misidentification or medical identity theft is discovered
- Individuals' access to personal health information via the HIE
  - How information is supplied to the requesting individual (web page, downloads to PHR or other, printing, etc)
  - What information is provided to the individual—all available, an abstract or both?
  - Authentication of individuals
  - Disclosure logs—minimum data set and retention requirements
  - Requests for changes and amendment to the record, how handled (e.g. patient directed to contact the provider supplying the information or does the HIO contact the provider on behalf of the patient and make any needed changes in the data; does this depend on the type of HIO and if so, what are the guidelines for each type)