



State Level Health Information Exchange

Final Report Part I: Roles in Ensuring Governance and Advancing Interoperability Executive Summary

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2 EXECUTIVE SUMMARY

2.1 INTRODUCTION

This report presents a synthesis of research findings, analysis, and recommendations from the 2007 work of the State-Level Health Information Exchange (HIE) Consensus Project (Project). The report is divided into two sections. The first addresses state-level HIE governance and sustainability considerations, as well as recommendations related to state- and federal-level HIE strategies. The second 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.

The 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 work through dissemination of field research and guidance materials and facilitation of broad stakeholder dialogue. A Steering Committee composed of leaders from state-level HIE entities plays a pivotal role in guiding and contributing research and analysis and formulating 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.*** Summarizes the Project's 2006-2007 research scope and findings, outlines the distinct value and characteristics of state-level HIE development, and includes an initial set of recommendations for activities to advance state-level HIE initiatives.
- ***Development of State Level Health Information Exchange Initiatives Final Report: Extension Tasks, January 2007.*** Reports on additional study 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 Initiatives Development Workbook: A Guide to Key Issues, Options and Strategies, February 2007.*** Established as an ongoing resource for state-level initiatives with practical policy and practice guidance regarding establishing state-level HIE governance, structure, operations, finance, and HIE policies. Includes profiles of the state-level initiatives represented on the Project's Steering Committee.

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

In its second phase of work, starting in March 2007, the Project 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 Project subcontracted with Manatt Health Solutions to lead Tasks 1 and 2 research efforts; AHIMA provided expertise for Task 3 research and analysis. Findings and recommendations related to Task 3 are reported in a separate section of this report. Stakeholder input was solicited at various stages from a panel of HIE experts and stakeholders; preliminary findings were disseminated through the Project's Web site and efforts by Project staff and partner organizations; and a two-day Consensus Conference was attended by more than 140 representatives from 18 states, providers, vendors, and various HIE constituencies including consumers and policy organizations. The Steering Committee, expanded from nine to 11 members, considered the research findings and stakeholder input to formulate points of consensus and recommendations, including considerations regarding policy issues to link this work with other state and national aspects of health information technology (IT) adoption.

2.2 KEY FINDINGS AND OBSERVATIONS

The focus of this Project is on activities organized at the state level to advance HIE. *State-level* is often confused with the work of *state governments*, who have important responsibilities related to promoting health and ensuring effective healthcare. This Project examines the unique roles of organized multisector public-private partnerships (PPPs) that facilitate collaboration and structure statewide HIE governance. These multistakeholder state-level entities range in their character and stages of development and may take on additional roles related to technical data exchange. However, they have important common features: a statewide mission for developing HIE to support healthcare improvement and a scope of HIE activity that addresses the unique needs and characteristics of the local, statewide, and potentially regional healthcare landscape.

The body of state-level HIE experiences is growing: three-quarters of states are pursuing strategies varying in levels of development and including the launch of HIE entities with goals to provide statewide governance and facilitate statewide interoperability. This activity is being fueled by the need to address concerns about the confidentiality and security of health records, acknowledged links between HIE and improving healthcare quality and efficiency, and pressures for healthcare reform.

Current research reinforces the importance of continued state-level HIE development. Findings focus on the key state-level HIE organizational roles that provide distinct value as part of an effective nationwide health information network. Project results point to a sense of urgency about preserving and expanding state-level HIE functions in order to achieve goals for developing widespread HIE that serves all stakeholders.

2.2.1 The Distinct Value and Organizational Roles for a State-Level HIE Governance Entity

There is growing consensus that a state-level HIE governance entity provides distinct and valuable functions that serve the public good. These include:

- ensuring that HIE develops beyond siloed corporate interests to serve all statewide stakeholders and their data needs;
- facilitating collaboration, rather than competition, related to data sharing to achieve the public good derived from mobilizing a full range of clinical and other information; and
- serving public policy interests and addressing consumer protection concerns by facilitating widespread and effective practices for maintaining the confidentiality of health information.

The state-level HIE governance entity sits between government and the healthcare sector with a mission to advance HIE by facilitating compliance with prevailing laws and regulations and sound data management practices and ensuring confidentiality and security protections. Experiences among states affirm that advancing statewide HIE requires a neutral and reliable source of leadership. Also critical are explicit coordination activities to facilitate data sharing across sectors and diverse interests, mobilize resources, and guide progress along a statewide HIE road map. Study informants indicate that an effective state-level governance entity must not be constrained by political variables or governmental budgetary constraints. Stakeholders perceive that even in states where government currently plays a key sponsorship role for early HIE efforts, it is most valuable for a state-level HIE entity to be a structure that engages, but sits outside of, state government.

2.2.2 Trends in State-Level HIE Organizational Models and Development

This study of state-level HIEs demonstrates that two key organizational roles are taking hold: governance and technical operations.

- The governance role consists of neutral convening and a range of explicit coordination activities that facilitate data sharing and HIE policies and practices among statewide participants.
- The technical operations role involves providing *state-level* technical services that enable statewide data sharing. Technical operations, including a range of health IT applications, can be owned and operated by the state-level organization or managed through contracts with outside technical providers.

The organizational configurations and developmental pathways for state-level HIE efforts reflect variable state cultures, resources, and mix of barriers and opportunities. However, prevailing trends can be observed from the Project's research.

- The governance role is primary across all states. Some state-level HIEs are structured to provide *only* the governance role. Others include both the governance and technical operations roles.
- Various factors influence whether a state-level HIE provides technical operations. These include state size, resources, and the particular strategies for interoperability that constitute the state's HIE road map. Many state-level HIEs indicate the likelihood of eventually providing some type of state-level technical support, either directly or through contracts. Some state-level HIE efforts are influenced by healthcare environments and medical trading

areas¹ that span state boundaries. They are considering governance and technical roles and strategies capable of supporting HIE across regional and other boundaries.

On the basis of studying state-level HIE experiences, a key factor in progress toward interoperability is an effective partnership between state government and a state-level HIE entity.

- Research illustrates how some state governments are playing vital roles in fostering HIE adoption. State agencies, particularly Medicaid, are becoming increasingly active in contributing to, and even leading, HIE development efforts. Governors and state policy makers are taking further steps to foster state-level HIE adoption by providing resources, sponsoring statewide road maps for HIE development, and seeking to codify state-level HIE functions within statutory frameworks.
- Study participants indicate that the most effective and desirable legal structure for a state-level HIE governance organization is an independent nongovernmental PPP entity. However, it is important for state government to provide a necessary level of empowerment through designation of authority and financial and nonfinancial support, including facilitating coordination and participation across agencies and executive branch policies and practices.

2.2.3 Services, Business Models, and Sustainability Considerations

Despite the high-profile failures of some HIE endeavors, numerous state-level initiatives stand poised to begin or expand exchange.² This study highlights the urgent need to develop value propositions and business models demonstrating HIE value across a continuum of local, state, and national levels to justify multistakeholder investments for full implementation and long-range sustainability.

Previous Project research that profiled the results of more mature HIEs revealed that key HIE services offered through a state-level HIE can be sustainable when the value proposition can be demonstrated. Attention is now being focused on the need for more robust studies of the impact of HIE across various levels of healthcare and for various HIE stakeholders. This study demonstrates that the perceived value of the public good that a state-level HIE provides is generating start-up support for state-level HIE efforts from public-sector sources. However, there is an urgent need to address how state-level HIE roles and functions can achieve long-range support to become fully implemented and to sustain operations. Study participants pointed to barriers that must be addressed, including mounting pressures from corporate health IT interests and continued resistance to full participation by key stakeholders, particularly private payers. Other barriers include the lack of clearly aligned federal incentives that can drive support for state-level functions that support healthcare transformation (e.g., quality and transparency initiatives and Medicaid information strategies).

¹ *Medical trading area* refers to an area where a population receives the majority of their healthcare provided by particular groups of physicians, hospitals, laboratories, mental health providers, and other healthcare providers offering services in that area. *Health Information Exchange: From Start Up to Sustainability*, prepared by the Foundation for eHealth Initiative for the HHS Health Resources and Services Administration (May 2007).

http://ehr.medigent.com/assets/collaborate/2007/07/10/Health_Information_Exchange-Start_Up_to_Sustainability_Full_Report_07.09.2007001.pdf

² See Table of Technical Operations in Appendix B.

Research findings and stakeholder input affirm emerging consensus that financing models for the implementation and sustainability of statewide HIE must be a blend of private and public investments.

- It is important that providers and healthcare data-sharing partners within medical trading areas invest in HIE in order to realize the benefits of improved patient care and operational efficiencies within their particular organizations and health systems.
- However, the state-level HIE plays a key role in achieving the broad benefits of HIE for a wide range of stakeholders, communities, organizations. In addition to supporting patient care, the state-level HIE can facilitate data sharing that supports statewide programs such as Medicaid, as well as public health, research, and quality reporting.
- The state-level HIE provides value by leveraging shared public-private sector investments to expand data sharing, reduce the technology investment costs for all participants, and ensure effective statewide HIE data-sharing policies and practices that protect confidentiality.
- Sustaining state-level HIE functions requires harnessing defined contributions from the broad range of HIE beneficiaries, including payers, business, and the general public/consumers, all of whom benefit from the unique role of the state-level HIE entity in serving the public good.

2.2.4 Building the Network of Networks

One key to state-level HIE sustainability is the ability to participate in a nationwide network. The Project Steering Committee was charged with discussing the advisability of some form of accreditation and the criteria for participation by state-level and local HIE entities to connect to a network of networks.

The Steering Committee acknowledged that defining baseline criteria for the roles and responsibilities of HIE organizations that can apply across various states and healthcare environments is important to promote consumer confidence and widespread HIE adoption.

The Steering Committee reached agreement on the need to define how state-level HIE organizations will participate in a nationwide HIE infrastructure (NHIN).

- This is a pivotal time for drawing together across sectors, HIE projects, and levels of efforts to develop a common framework for sustainable HIE functions, roles, and accountability so that a patchwork of variable state statutory frameworks for HIE definitions and organizational requirements can be avoided.
- Aligning the efforts by various federally sponsored HIE initiatives is important to provide clarity and help to channel the participation and support of statewide constituents.

The Steering Committee emphasized that reliance on a public-private model for HIE governance has significant public policy implications. On the basis of several considerations, preliminary consensus was reached that a system of accreditation for state-level HIE entities is an advisable strategy warranting further research to assess its feasibility.

- Accreditation is a recognized method by which to assess and benchmark organizational practices against emerging best practice standards. Understanding experiences with accreditation and quality improvement can help to design effective accountability mechanisms applicable to HIE. These lessons include the value of starting small,

- building an iterative process that can include public input, and focusing on assessing functions that occur across particular types of defined organizational boundaries.
- Accreditation is distinct from the national-level system of certification being developed to verify the capacity of electronic medical record (EMR) products and HIE networks. Verifying the adequacy of organizational roles and functions such as those anticipated for state-level HIE organizations requires the ability to assess the effectiveness of processes for policy development and the impact of these and other organizational practices on meeting HIE goals.
 - Accreditation can accommodate the nascent stage of HIE organizational development and help to incrementally apply emerging standards for organizational roles and functions. As a self-regulatory mechanism, accreditation at a national level could apply to entities connecting as part of the NHIN. Some question whether state-level HIEs could also serve as mechanisms to oversee HIE practices in local or regional entities.

The Steering Committee advised that additional research is necessary to address key issues including how best to define, structure, and implement HIE accountabilities and oversight mechanisms. The Steering Committee also emphasized the need to link development of an accreditation mechanism to the realistic needs and expectations of the customers for this process. It is important to ground the development of any accreditation and accountability mechanisms within the realities of the healthcare landscape and HIE business and operational concerns—local, state, and nationwide. Issues to be addressed include the timing and developmental readiness of HIE organizations and whether incentives for seeking accreditation are aligned with the economic viability of HIE organizations. Important questions relate to what specific steps should be taken by Medicare, Medicaid, and other federal-level agencies and HIE initiatives to align their incentive strategies and program requirements (e.g., health IT reimbursement, quality and transparency initiatives) to support adoption of structured expectations and oversight strategies.

2.2.5 Policy Recommendations for the American Health Information Community

Over the next six months, a successor to the current American Health Information Community (AHIC) is being designed as a private-sector entity in which the federal government will participate. The roles of states and state-level HIEs should be an early consideration. State-level activities, particularly the activities of private-sector state-level HIEs, have been missing from the current AHIC, which has functioned as an advisory body to the Secretary of Health and Human Services (HHS). The AHIC successor is envisioned as the multistakeholder entity to set directions and standards for nationwide HIE. The Steering Committee has emphasized the need for this entity to be sufficiently inclusive and empowered to impact the course of HIE development across relevant levels of activity.

State-level HIEs, distinct from other state interests, must be viewed as stakeholders in the design and implementation of the AHIC successor. The Project's research demonstrates that the state-level HIE entity can represent an effective link to understanding the stages of HIE development and readiness within and across statewide health environments, including both local and regional dimensions and public and private-sector characteristics. State government is clearly another important HIE stakeholder. State public health and Medicaid agencies have roles in promoting data sharing. However, a state-level HIE governance entity inherently incorporates all state-level perspectives as part of its mission and activities to foster a statewide system for interoperable HIE.

State-level HIEs can serve as a vital laboratory for informing, vetting, and advancing AHIC priorities.

2.3 RECOMMENDATIONS

This phase of the Project identified both forward momentum and continuing challenges in advancing statewide interoperability. States are increasingly active in promoting HIE strategies and establishing HIE governance mechanisms. Federal leadership has spurred expanded state-level participation in key projects to inform national-level HIE policy development, standards, and criteria for demonstrating interoperability. Current NHIN demonstrations involve state-level HIE, and this Project's efforts are helping to understand and develop the data access, use, and control policies and practices necessary for interoperability across HIEs as part of the NHIN. Importantly, knowledge sharing among state-level HIE initiatives has increased, and its importance has been validated, through the mechanism of this Project, its Steering Committee, and ongoing outreach.

However, findings from the current study point to important issues that require additional research, policy direction, and the benefit of further time and experience before becoming fully clarified.

- It is important to define structures and accountabilities for HIE entities that are linked to incentives and resources that support the sustainability of invaluable state-level HIE functions. The still nascent stage of much HIE development must be accommodated while reliable mechanisms for monitoring, oversight, and accountability are established as part of formal HIE requirements and organizational structures.
- Key issues identified in the Project's 2006 work remain to be addressed. These include the need to engage and align public and private payers with state and federal efforts to advance interoperability. At a national level, the roles for Medicaid and Medicare in helping to build and sustain HIE capacity must be clarified and strengthened. The active engagement of health plans in strategies to support state-level HIE remains an important priority.
- An updated federal HIE strategy is important to clarify the balance among local-, state-, and national-level activities and relationships. A multitude of development projects are under way that involve states and state-level HIEs. However, it remains unclear how state-level HIEs will relate to the NHIN—alone or with contiguous states. Coordinated governance across state and national levels will be important to avoid fragmented and incomplete HIE development. The respective roles of state and federal governments must be clarified related to HIE policy development and governance.
- Work is urgently required to outline the value proposition for HIE governance and technical roles and activities that span local, state, regional, and nationwide HIE data-sharing interests and relationships. Models for building and sustaining HIE capacity must be advanced that include support for broad public policy goals and appropriate governance functions.

The following set of recommendations draw from this study and stakeholder input. They provide guidance for state- and federal-level HIE efforts to advance key priorities for ongoing HIE development.

RECOMMENDATIONS TO STATE GOVERNMENTS AND STATEWIDE HIE STAKEHOLDERS	
State-Level HIE Governance	1. As part of a defined road map for achieving interoperability, each state should take steps to facilitate and support implementation of defined HIE governance roles

	<p>and functions.</p> <ul style="list-style-type: none"> a. State government and healthcare stakeholders should support and participate in a single, state-level public-private entity that takes on a distinct state-level HIE governance role. b. State governments (e.g., governors, legislators, agencies) should take appropriate steps to recognize a statewide HIE governance entity; provide funding; structure its authority to enable it to receive particular types of benefits, financial and otherwise; and define its accountabilities related to state policy goals and related statutory requirements. c. State governments should designate a point of coordination across government agencies and public programs that will be responsible for working in concert with the state-level HIE governance organization to advance the state’s HIE implementation road map and help promote coordinated public-sector HIE policy development.
<p>HIE Services, Business Models, Sustainability</p>	<p>2. State-level public programs and agencies should work in partnership with state-level HIE entities and leverage their influence to build and sustain governance and statewide technical interoperability.</p> <ul style="list-style-type: none"> a. As part of a state’s HIE road map, public health and Medicaid HIE strategies should be linked to support the value proposition for a sustainable state-level HIE entity. b. States should promote demand for health information among statewide constituents and foster data sharing among the state’s major data contributors that will mobilize data currently fragmented in data silos.
<p>Building the Nationwide Network of Networks</p>	<p>3. States should align their approaches for establishing HIE policy related to interoperability standards, confidentiality provisions, and criteria for HIE entities with emerging efforts across states and at the national level.</p> <ul style="list-style-type: none"> a. State-level HIE road maps should incorporate explicit strategies and timelines to take advantage of current initiatives and emerging multistate and national-level development.
<p>RECOMMENDATIONS FOR NATIONAL-LEVEL ACTION (BY AHIC, ONC, AND OTHER FEDERAL HIE INITIATIVES)</p>	
<p>HIE Services, Business Models, Sustainability</p>	<p>1. Take urgent steps to define multilevel HIE value propositions and related sustainability models that will foster nationwide interoperability.</p> <ul style="list-style-type: none"> a. Develop a coordinated research agenda to support impact and evaluation studies by which to understand how and where HIE accrues value. b. Support a collaborative process and engage key expertise and stakeholders, including state and federal government; private-sector interests; and local-, state-, and regional-level HIEs, to develop, test, and vet options for blended public-private funding models that capture relative contributions across a range of HIE participants and beneficiaries. c. Define an aggressive workplan with clear time frames, deliverables, and project management to ensure that state-level HIE efforts and other crosscutting infrastructure development (e.g., NHIN and AHIC, Centers for Medicaid and Medicare Services CMS, Centers for Disease Control [CDC], Agency for Healthcare Research and Quality [AHRQ]) work in

	<p>concert.</p> <p>d. Actively monitor, synthesize, and disseminate findings to promote consensus building.</p>
<p>HIE Services, Business Models, Sustainability</p>	<p>2. Build upon the Project’s research, analysis, and mechanisms for stakeholder engagement to continue and enhance monitoring and assessment of HIE development across states.</p> <ul style="list-style-type: none"> a. Promote development of a well-articulated framework that categorizes emerging phases of HIE development, including levels and types of HIE technical and organizational development. b. Develop a methodology to monitor and benchmark milestones for local, statewide, regional, and nationwide HIE development efforts. c. Actively monitor, synthesize, and disseminate findings to promote consensus building for HIE sustainability and to guide emerging states and inform federal HIE initiatives.
<p>Building the Nationwide Network of Networks</p>	<p>3. Establish a structured collaborative process to develop and vet options for an accountability structure that incorporates the roles and contributions of HIE entities at various levels, including state-level HIE governance entities.</p> <ul style="list-style-type: none"> a. Identify a set of options for structuring and maintaining accountability and oversight for key HIE functions and organizational roles, including regulatory and accreditation models. b. Develop standards and associated qualification criteria and methods for accrediting HIE entities related to key HIE functions and state-level HIE organizational roles (governance and technical operations). c. Structure appropriate time frames and approaches for implementing standards and accountability mechanisms, including certification, accreditation, and statutory/regulatory oversight, that accommodate the nascent stages of HIE development and create appropriate incentives.
<p>Building the Nationwide Network of Networks</p>	<p>4. Strengthen and enhance mechanisms to promote strategic synergy between state and federal HIE agendas and initiatives.</p> <ul style="list-style-type: none"> a. Build upon the Project’s success in convening state-level HIE leaders to continue and expand the communication and coordination among states and between states and federal agencies. Continue to support expanded dialogue and consensus building among states and provide a defined voice for state issues in the emerging federal HIE agenda. b. Structure mechanisms to involve state-level HIEs and the Project more effectively as part of ongoing NHIN development. c. Structure explicit mechanisms to bring together federal agencies and offices to communicate and coordinate HIE agendas and foster alignment of support for HIE development, including state-level HIE, Medicaid, Medicare, Health Resources and Services Administration (HRSA), and AHRQ. d. Work actively with representatives of governors and elected officials to define and foster communication, coordination, and alignment across emerging strategies that incorporate and support the roles of state-level HIE entities.

	<p>e. Support efforts to clarify and vet options for a lexicon of defined HIE terms, roles, and functions.</p>
<p>ADDITIONAL POLICY RECOMMENDATIONS TO AHIC</p>	
<p>Establishing Nationwide HIE Governance</p>	<ol style="list-style-type: none"> 1. Define the roles and relationships of state-level HIE entities as part of the design and implementation of an AHIC successor as a permanent nationwide HIE governance entity. <ol style="list-style-type: none"> a. State-level HIEs should be involved in designing the AHIC successor to help address issues related to the landscape of HIE development and roles for local, state, and regional PPPs. b. State-level HIEs must have a formal way to be represented in the ongoing activities of AHIC. c. The Project should be called upon as a mechanism to help develop and vet options for structured state-level participation, including efforts to engage other key state-level HIE constituents such as Medicaid and public health directors and policy makers who currently support and participate in state-level HIE efforts.