



State Level Health Information Exchange

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

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**Findings and Recommendations from the
State Level Health Information Exchange
Consensus Project
March 2008**

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Roles in Ensuring Governance and Advancing
Interoperability**

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Table of Contents

1	ACKNOWLEDGMENTS	4
2	EXECUTIVE SUMMARY	6
2.1	INTRODUCTION	6
2.2	KEY FINDINGS AND OBSERVATIONS.....	7
2.2.1	The Distinct Value and Organizational Roles for a State-Level HIE Governance Entity	8
2.2.2	Trends in State-Level HIE Organizational Models and Development	8
2.2.3	Services, Business Models, and Sustainability Considerations	9
2.2.4	Building the Network of Networks.....	10
2.2.5	Policy Recommendations for the American Health Information Community	11
2.3	RECOMMENDATIONS.....	12
3	BACKGROUND	16
3.1	THE EVOLVING HIE LANDSCAPE.....	16
3.2	PROJECT GENESIS AND 2006 RECOMMENDATIONS.....	17
3.3	2007 PROJECT GOALS AND SCOPE	18
4	PROJECT METHODOLOGY.....	20
4.1	RESEARCH APPROACH	20
4.1.1	Task 1: Governance Roles and Functions.....	20
4.1.2	Task 2: State-Level HIE Services and Sustainability Factors	21
4.1.3	Task 3: HIE Policies and Practices	21
4.2	CONSENSUS CONFERENCE	22
4.2.1	Program and Attendees	22
4.3	DISSEMINATION OF PROJECT RESEARCH, RECOMMENDATIONS, REPORTS, AND RESOURCES	23
4.4	PROJECT TEAM	23
5	KEY OBSERVATIONS.....	25
5.1	TASK 1 FINDINGS	25
5.1.1	Governance a Driver for State-Level HIE Development.....	25
5.1.2	Core State-Level HIE Organizational Roles and Functions	26
5.1.3	Priorities for Implementing State-Level HIE Governance	28
5.1.4	Key Elements of Effective Organizational Models	29
5.2	TASK 2 FINDINGS	31
5.2.1	Prevailing Organization Models and Developmental Pathways.....	31
5.2.2	Sustainability Considerations.....	32
5.3	BUILDING THE NETWORK OF NETWORKS	33
6	RECOMMENDATIONS	36
7	APPENDIX A - CONTINUED DEVELOPMENT OF STATE-LEVEL HIE EFFORTS.....	40
8	APPENDIX B - STATE-LEVEL HIE TECHNICAL OPERATIONS	42
9	APPENDIX C - PROFILES OF STATE-LEVEL HIE: SOURCES AND MECHANISMS FOR STATEWIDE AUTHORITY.....	45

10	APPENDIX D - PROFILES OF STATE-LEVEL HIE: ORGANIZATIONAL MODELS AND DEVELOPMENT PATHWAYS	47
11	APPENDIX E - BIBLIOGRAPHY	62
12	APPENDIX F - LIST OF CONTRIBUTORS AND RESPONDENTS	73
13	APPENDIX G - RESEARCH QUESTIONNAIRES	76
14	APPENDIX H - RATIONALE FOR SELECTION OF STATES FOR RESEARCH COHORT	98

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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.

3 BACKGROUND

3.1 The Evolving HIE Landscape

In states and communities across the country, stakeholders are coming together to build data-sharing systems to improve the quality, safety, and efficiency of healthcare services. Local HIE efforts vary in their technology models and participants but generally tend to represent organized partnerships between providers whose business models are based on serving distinct locales and populations. These service and business affiliations have recently been labeled *medical trading areas*.³ Recent high-profile failures of some HIE efforts have raised questions about the scale and viability of the broader regional health information organization (RHIO) as a construct for an interconnecting NHIN. Persistent challenges in mobilizing resources to support the desired pace and scope of HIE adoption are dampening optimism about what can be accomplished to interconnect the country beyond these limited HIE connections between corporate interests.⁴ Concern about empowering the consumer as the locus of control over health information is generating interest in other technical HIE models such as health-record banks.

In this context, state-level HIE initiatives⁵ continue to emerge between the national- and local-level efforts to catalyze statewide HIE development. Three-quarters of states are pursuing HIE strategies of some kind that vary considerably in their level of development. Growing interest in HIE as a healthcare reform priority has resulted in the introduction of more than 200 bills focused on health IT in 41 states since January 1, 2007.⁶

The federal government continues to spur interoperability by sponsoring projects to address interrelated aspects of a nationwide HIE infrastructure that link sectors and their appropriate resources, influence, and accountabilities.⁷ Through a variety of federal contracts, state constituencies are involved in field research, analysis, and demonstration projects.

- As part of the Health Information Security and Privacy Collaboration (HISPC), 33 states and one territory have assessed the variations in HIE privacy and security practices and policies and developed practical solutions and implementation strategies.
- The State Alliance for eHealth is exploring public-sector HIE roles and participation by state governments and policy makers, Medicaid and other public programs, and other issues such as workforce licensing and clinical practice considerations.

³ *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.

⁴ Glaser, John. *The Advent of RHIO 2.0*. Journal of Health Information Management, Vol 21,#3, Summer 2007. www.himss.org.

⁵ For the purposes of this document, *state-level HIE initiative* means a HIE initiative or organization that is statewide in scope, involves some form of public-private collaboration, partnership, or governance, and which could be facilitating the exchange of clinical data and/or administrative data.

⁶ *eHealth Initiative BluePrint: Building Consensus for Common Action*. eHealth Initiative (October 10, 2007). <http://www.ehealthinitiative.org/blueprint/eHiBlueprint-BuildingConsensusForCommonAction.pdf>.

⁷ An overview of federal efforts to support HIE is available on ONC's Web site at <http://www.hhs.gov/healthIT>.

- Six state HIE initiatives with State and Regional Demonstration Project contracts from HHS are moving forward with plans and implementation of HIE within their states. These state projects are helping inform business-model development as part of the emerging HIE Value and Sustainability Model promulgated by electronic health information (eHI) in conjunction with the AHRQ and National Resource Center.
- Thirteen state Medicaid agencies are using their Centers for Medicare and Medicaid Services Medicaid Transformation Grant awards to advance HIE efforts within their states.
- Current NHIN trial implementation projects involve state-based HIE development.^{8,9}
- A plan is under way to establish a permanent public-private governance structure at the national level as the successor to the AHIC 2.0¹⁰ that will involve representation of state-level interests.

Activities and time frames for establishing national standards, certification processes, and nationwide HIE efforts (both NHIN and AHIC) set a broad context and heighten the relevance of this Project's scope of work.

Efforts to describe and categorize HIE development are challenged by an unsettled lexicon related to HIEs and RHIOs. Although *states* is often used to refer to state governments, *state-level HIE* refers to state-level organizational entities ranging in structure and development but having key dimensions. These core features include a statewide scope and some form of multisector public-private collaboration, partnership, or governance that includes participation by state government representatives. The roles and functions of these important state-level HIE entities, as well as implications for their place in widespread HIE development and sustainability, are the subject of this study.

3.2 Project Genesis and 2006 Recommendations

This Project began in 2006 under a contract from ONC with AHIMA-FORE. The Project was chartered to help understand prevailing strategies, opportunities, and challenges related to these emerging organized, state-level efforts to advance statewide HIE. In particular, the Project is focused on bringing forward relevant formative field research, guiding ongoing HIE development among states, informing federal-level HIE strategies, and helping to align multilevel efforts toward a NHIN.

As its first task, the Project examined nine state-level HIE initiatives at various stages of development; in different regions of the country; and with different state economic, demographic, and healthcare market characteristics. A Steering Committee composed of leaders from these diverse state initiatives led this task, and a series of reports and recommendations were produced to help guide both state and national thinking and HIE development efforts.

The 2006 Final Report synthesized key findings and pointed to valuable and distinct HIE functions taking place at the state level to organize and lead the inherently collaborative business of

⁸ *Summary of the NHIN Prototype Architecture Contracts*, prepared by Gartner for the Office of the National Coordinator for Health IT (May 2007).

http://www.hhs.gov/healthit/healthnetwork/resources/summary_report_on_nhlin_Prototype_architectures.pdf.

⁹ Descriptions of these and other efforts are available online at the HHS Health Information Technology Web site at <http://www.hhs.gov/healthit/>.

¹⁰ Additional information on AHIC is available online at <http://www.hhs.gov/healthit/community/background/>.

implementing and managing health data exchange. Barriers to HIE development were identified, including lack of funding, lack of consensus about roles and participation across public and private sectors, and lack of strategic alignment between states and the long-range federal NHIN strategy. Key guidance and points of consensus regarding state-level HIE organizing principles, design features, and other lessons learned about approaches to state-level HIE development were compiled into a Workbook and disseminated as a resource for emerging state-level HIE efforts.

In an extension of its 2006 scope of work, the Project conducted additional research and produced commentary regarding the relationship of state-level HIE efforts to the emerging nationwide HIE landscape. The Steering Committee emphasized that achieving strategic HIE goals for widespread interoperability is part of a broader agenda for healthcare transformation. Building a HIE infrastructure requires understanding the interplay and structuring alignment of multilevel policy; governance; and operational roles, priorities, and resources. Other specific points included the following:

- Leadership at both state and national levels is required to integrate HIE quality and value initiatives as part of a transformational agenda. State-level HIE entities are poised to play this role.
- Pressures are increasing to understand and establish the key factors influencing the value proposition for HIE sustainability. The Steering Committee highlighted the urgent need to engage and leverage the full participation and support of public and private sectors, especially payers, and showed that this support is vital for defining the value propositions that will achieve HIE sustainability.

The Steering Committee urged that steps be taken to solidify a nationwide HIE infrastructure, clarifying roles and thus channeling resources to support the sustainability of HIE endeavors. These recommendations generated a set of overarching questions as a springboard for additional HIE development activities:

- What essential HIE roles and responsibilities should be endorsed and/or codified for different types and levels of HIE organizations?
- How can resources be channeled to build and sustain these levels of organizational HIE capacity and achieve necessary levels of scale?
- How should the HIE policy environment be aligned to create positive financial and nonfinancial incentives and facilitate local, state, regional, and national interoperability?
- What business model(s) will support multilevel HIE functions?
- How should appropriately defined HIE entity qualifications, accountabilities, and oversight mechanisms be established?

All reports and resources from the first phase of the Project are available at <http://www.staterhio.org>.

3.3 2007 Project Goals and Scope

To continue learning from diverse state-level HIE environments and address these issues, ONC chartered a second phase of the Project targeting these questions regarding the evolving HIE infrastructure.

In March 2007, the Project embarked on its second phase of work to accomplish the following:

1. Clarify further the distinct and necessary functions of state-level HIE initiatives and how they relate to other types of HIE entities (e.g., local, regional, and national levels).
2. Assess the institutional and financial implications for implementing and sustaining HIE functions performed by state-level HIE, including policies and practices related to data access, use, and control.
3. Begin to define a framework for accountability taking into account the various roles and functions of state-level HIE and other types of HIE entities and the realities of HIE development and state-level needs, boundaries, and policy and program parameters (e.g., Medicaid, public health, data reporting).
4. Build consensus for the appropriate functions, qualifications, and support needed for state-level HIE entities in the context of a multilayered HIE infrastructure.

The scope of this year's Project consisted of a series of research, analysis, and dissemination activities to expand the range of input and critical thinking regarding how state-level HIE efforts can best support valuable HIE functions into the future. This process included expanding the number of states involved and outreach to HIE leaders, experts, and key stakeholders. It also included gaining a deeper understanding of successful governance and financial and operational characteristics related to achieving statewide goals for interoperability.

The work was aided by expanded collaboration with eHI, Healthcare Information and Management Systems Society (HIMSS), and National Conference of State Legislatures (NCSL) as partners in broadening the state-level HIE learning community. These collaborations were a valuable two-way path to staying abreast of developments in states, as well as of other research being done, and provided a channel for disseminating the work of the Project.

The Project team also coordinated its efforts with other parallel HIE projects and initiatives funded by ONC and other agencies and built upon the research and expertise of AHIMA related to health information management policies and practices. Some of the issues considered in conjunction with other Project teams included public versus private-sector HIE roles, HIE policy particularly related to privacy and security, and the relationship of HIE to quality and transparency efforts.

4 PROJECT METHODOLOGY

The Project relied on an iterative process of research, analysis, dissemination, and feedback to develop emerging points of consensus and areas for further dialogue and development. Throughout, the Project Steering Committee provided guidance to inform and participate in the research design, analyze findings, and respond to stakeholder input as points of consensus developed.

The research was organized into three defined tasks and divided into two workplans managed by separate research teams.

Tasks 1 and 2 Research team: Manatt Health Solutions

- Examine dimensions of the state-level HIE governance role and its implications
- Identify the implications of state-level HIE services for business models as part of HIE sustainability

Task 3 Research team: AHIMA

- Identify issues related to ensuring a sound framework of HIE policies and practices

Tasks 1 and 2 were addressed as part of a continuum of incremental research, analysis, and input. Early in the first phase of Task 1 research, a reactor panel representing diverse stakeholder perspectives and expertise related to HIE development was convened to inform the research framework and react to initial formulations of governance roles and implications. A report of preliminary Task 1 findings was released and circulated for comment through a variety of venues, including Project partner efforts, as research into Tasks 2 and 3 continued. A Consensus Conference was convened to review additional findings from Tasks 1 and 2 and to identify emerging points of consensus, debate, and need for further investigation. This input was considered by the Steering Committee in formulating final Project recommendations.

Subsequent to the launch of this scope of work, the Task 3 workplan was revised in light of other emerging projects analyzing HIE data stewardship and the launch of the second round of NHIN demonstration projects. The Steering Committee informed the research plan, and Consensus Conference attendees provided input to inform the ongoing Task 3 research.

In light of this Project design, the Project Final Report consists of two sections. The first part addresses state-level HIE governance, organizational roles, and sustainability issues. The second part addresses Task 3 research, analysis, and recommendations. A companion update to the 2007 Workbook will be a resource for developing state-level HIE organizations on the basis of the Project findings and Steering Committee guidance.

4.1 Research Approach

4.1.1 Task 1: Governance Roles and Functions

The first task was to expand understanding of the roles and functions of state-level HIE entities, especially in providing governance for statewide HIE activity. The research cohort included the original nine states in the first phase of the research (California, Colorado, Florida, Indiana, Maine, Massachusetts, Rhode Island, Tennessee, and Utah) and expanded to involve six additional states (Arizona, Kentucky, Louisiana, Michigan, New York, and Washington). Selection criteria and rationale are provided in Appendix H.

The research team reviewed materials derived from national, state, and local sources to inform state profiles on HIE initiatives and to collect background information on each state's current healthcare landscape. Beginning in May 2007, the research team conducted semistructured telephone interviews with leaders of the 15 state-level HIE efforts to obtain updated information on such topics as their mission, vision, and sources of authority; rationale for choice of entity; extent of local and state stakeholder participation in the entity; and the nature of the interaction with local HIEs.

The Project convened a reactor panel to gather feedback on the governance research findings. Experts representing various stakeholder groups participated in a two-hour conference call on May 31, 2007 (participants are listed in Appendix F).

A preliminary report entitled *State Level Health Information Exchange: Roles in Ensuring Governance and Advancing Interoperability (Preliminary Report)* was released in September 2007 and highlighted the governance role of state-level public-private entities in advancing statewide collaboration and HIE development, especially related to ensuring privacy and security protections. Several action steps were proposed, including steps for state government that would strengthen public-private sector support for the vital HIE governance functions. These were discussed and vetted for inclusion as part of this final set of conclusions and recommendations.

4.1.2 Task 2: State-Level HIE Services and Sustainability Factors

As the preliminary governance research findings and report circulated for comment beginning in September 2007, the research team launched an expanded analysis of the state-level HIE roles and functions supporting statewide interoperable HIE. As a first step, the Steering Committee provided information on the relative rank of each function in terms of criticality, the resources required to fulfill the function, and the entities that are currently and will likely support this function in the future. The template used by the research team to gather information is provided in Appendix G. Key stakeholders, listed in Appendix F, provided feedback to validate the ability and appropriateness for state-level HIEs to fulfill various roles and functions.

The research team conducted an in-depth analysis of three states through semistructured interviews with representatives from key stakeholder groups at the state and local levels. This analysis was done to gain a richer understanding of the state-level HIE efforts' relationships with other entities. The three case studies, Massachusetts, New York, and Washington, were selected based on the maturity of the initiatives, the range of existing or proposed functions and services, and the diversity of the business models.

Finally, the research team supplemented its case study analysis by soliciting perspectives on the value of various roles and functions offered by state-level HIEs from RHIOs, Value Exchanges, regional provider networks, national data networks, and aggregators of health information for claims, research, and so on. A list of interviewees is provided in Appendix F.

4.1.3 Task 3: HIE Policies and Practices

Policy coordination is a significant role for state-level HIE entities. This Project research task focused on developing guidance for structuring effective policies for data access, use, and control within and across HIEs as interoperable data sharing begins to occur in different scenarios.

The Task 3 methodology built upon the body of information developing from other related important efforts including the Connecting for Health Common Framework, NHIN prototypes, HISPC, and Health Information Technology Standards Panel (HITSP). The analysis used sample scenarios arising from the NHIN implementation projects and applicable to emerging HIE efforts across states to assess factors relevant to appropriate data access, use, and control.

A multidimensional analysis of these factors at the operational level produced specific and detailed findings to 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.

Task 3 research and analysis is more fully described in Part II of this Final Report.

4.2 Consensus Conference

The second Project-sponsored Consensus Conference, *Building Sustainable Health Information Exchange: Roles for State-Level Public-Private Partnerships* took place November 5-6, 2007, in Washington, DC. The event elicited stakeholder input based on the Project's research and preliminary observations.¹¹ This conference offered an important opportunity for direct dialogue among diverse participants to consider the implications of state-level HIE governance roles and functions, inform understanding of sustainable organizational models, and continue to build a base of support for key state-level HIE functions and HIE infrastructure considerations. Points of consensus and debate and areas for additional investigation were recorded and are reflected in these findings, analysis, and overarching recommendations.

4.2.1 Program and Attendees

More than 140 attendees included representatives of 18 states, providers, vendors, and various HIE constituencies, including consumer and policy organizations.

Conference objectives targeted:

- Dissemination of the latest research on how state-level HIE roles and functions are evolving and implications for building and sustaining valuable state-level HIE services
- Talk with state-level HIE leaders about what they are learning about how to shape their organizations
- Stakeholder input to build points of consensus about the essential value, characteristics, and resources for state-level HIE as part of the broad context for nationwide HIE
- Planning for future information needs and information sharing among state-level HIEs

The two-day conference agenda was structured to provide a timely overview of preliminary research findings and to foster dialogue and solicit input among a diverse learning community of HIE stakeholders. Dr. Robert Kolodner, National Coordinator for Health IT, set the stage for the proceedings by highlighting the crucial context of healthcare transformation and the multiple interrelated dimensions of achieving a cohesive nationwide framework for effective health information. State-level case studies were profiled to illustrate how governance roles are playing out within various statewide healthcare environments. Breakout sessions provided an opportunity for attendees to discuss and make recommendations regarding governance, HIE services and business

¹¹ Presentations and additional conference materials, including the conference agenda, are available at <http://www.staterhio.org/conference/pre.asp>.

models, and issues related to establishing HIE policies and practices across diverse data-sharing partners. The second day provided an opportunity for the audience collectively to review and react to the compiled points of consensus and debate and areas for future research. A reactor panel of HIE experts, states, and perspectives also provided commentary.

4.3 Dissemination of Project Research, Recommendations, Reports, and Resources

The 2007 Project scope of work relied on a strategy for ongoing dissemination of project findings and gathering of input to foster consensus related to state-level HIE organization roles and sustainability. The Project director and Steering Committee members helped to widen the discussion and involvement of diverse stakeholders in reacting to the evolving Project findings and recommendations.

The Project provided commentary to inform the deliberations of other key projects and initiatives, including the State Alliance for eHealth, the Certification Commission for Health IT (CCHIT), and HISPC.

The Project participated in a partnership with key organizations to coordinate Project activities, disseminate information, and collaborate to advance sustainable HIE development. These Project partners include HIMSS, eHI, and NCSL. The Project also has staff liaison relationships with HISPC, RTI International, ONC, and AHRQ.

This final two-part Project report incorporates a synthesis of Project research findings and observations and lays out observations and recommendations for strengthening and sustaining state-level HIE functions in the current context of evolving state- and national-level issues. The first part replaces the September 2007 preliminary report entitled *State Level Health Information Exchange: Roles in Ensuring Governance and Advancing Interoperability (Preliminary Report)*, as well as the *Consensus Conference Workbook* distributed as part of the Project's November 2007 Consensus Conference.¹²

The 2007 Project research findings will be incorporated into the online 2008 Project Workbook. This Workbook is a companion to the original Project Workbook and is being made available as a resource to inform developing state-level HIE efforts.

All Project reports and materials are available at www.staterhio.org. Inquiries should be forwarded to info@staterhio.org.

4.4 Project Team

As mentioned, the phrase *Project Team* refers to the Project staff, Steering Committee, and Technical Advisors who participated in this Project. The director for this Project was Lynn S.

¹² Because of the Project's previous findings and early 2007 governance field research, the *Preliminary Report* outlined a framework for categorizing state-level HIE functions and formalizing organizational and sector roles and responsibilities. The Consensus Conference Workbook included additional preliminary research findings and served as a resource to support stakeholder discussion and consensus development regarding state-level HIE roles and functions and the emerging nationwide HIE infrastructure.

Dierker, RN. Other project staff from AHIMA and FORE assisted her in project planning, data collection, review of draft documents, conference preparation, and project management.

The senior leaders of 11 state-level HIE initiatives were invited to serve on a Steering Committee for the Project. This Steering Committee included the nine states that had participated in the 2006 Project, as well as the addition of the states of Louisiana and New York. The expansion of this Steering Committee recognized both the continuing quality of input and thought leadership provided by the original Steering Committee and the need to include ever more diverse input from other state-level HIEs as they reach critical stages in their development. During data collection, members of the Steering Committee provided information about their state-level HIE initiatives and participated in interviews. During data analysis, they served in a critically important advisory capacity in developing guiding principles, leading discussions at the public Consensus Conference, and formulating the recommendations presented in this Final Report.

NCSL brought invaluable perspective and expertise to the previous work under this Project. To this successful combination, this Project added formal participation by eHI and HIMSS to strengthen the level of collaboration for education and services to the HIE community. These organizations each provided representatives to participate in deliberations of the Steering Committee, share findings of interest from each organization's ongoing work related to HIEs, and provide venues for the dissemination and dialogue about this Project's findings.

The Steering Committee and Technical Advisors participated through in-person meetings, conference calls, and the public Consensus Conference. They reviewed drafts of the *State Level Health Information Exchange Initiative Development Workbook* update and offered guidance on this Final Report, including the plan for dissemination of the findings.

5 KEY OBSERVATIONS

Key findings emerge based on updated and expanded research and analysis of state-level HIE efforts. Invaluable input from the Project Steering Committee and an array of stakeholders, reactor panels, and more than 140 participants at the Consensus Conference corroborates, strengthens, and expands the Project's previous observations. This additional depth of analysis sharpens the focus on the nature and direction of state-level HIE contributions to the strategic nationwide HIE agenda for meaningful healthcare transformation.

5.1 TASK 1 FINDINGS

5.1.1 Governance a Driver for State-Level HIE Development

State-level HIE initiatives are continuing to develop and progress, despite unsettled aspects of the comprehensive, nationwide strategy for achieving widespread HIE. Pressures for healthcare reform, links between HIE and improving healthcare quality and efficiency, and the desire to address concerns about privacy and security are motivating state leaders to press forward with HIE strategies.

Key drivers for organizing and defining distinct state-level HIE activities include:

- The need to ensure that HIE develops beyond siloed corporate interests to serve the statewide public good: improving healthcare safety, quality, and efficiency and ensuring consumer protections related to privacy and security
- The perceived need and value of a statewide HIE governance role, especially to provide a source of neutral convening and coordination across diverse and sometimes competing stakeholders to ensure that statewide interoperability remains a shared goal
- The need for more clarity and defined accountabilities, especially for how oversight and monitoring of HIE policies and practices will occur in relationship to state- and federal-level healthcare oversight mechanisms

Three-quarters of states are pursuing HIE strategies of some kind, and they vary considerably in their level of development. Growing interest in HIE as a healthcare reform priority has resulted in the introduction of more than 200 bills focused on health IT in 41 states since January 1, 2007. Sixteen of these bills have been signed into law by the governors in 11 states.¹³ In 15 states, governors have issued executive orders designed to drive improvements in health and healthcare through the use of IT—eight in 2007 alone.¹⁴

On a continuum from early planning to operational implementation, many states are in early or foundational stages, and 18 state-level efforts are in pilot or full organizational implementation stages (governance and/or operations). Although few are currently exchanging statewide data, several state-level initiatives are poised to begin live data exchange over the course of 2008. See Appendices A, B, C, and D for a more detailed view of state-level HIE activity and the 2008 Workbook for more information about state HIE activities.

¹³ *States Getting Connected: State Policy Makers Drive Improvements in Healthcare Quality and Safety through IT.* eHealth Initiative (August 2006). <http://www.ehealthinitiative.org>.

¹⁴ *eHealth Initiative BluePrint: Building Consensus for Common Action.* eHealth Initiative (October 10, 2007). <http://www.ehealthinitiative.org/blueprint/eHiBlueprint-BuildingConsensusForCommonAction.pdf>.

5.1.2 Core State-Level HIE Organizational Roles and Functions

The growing momentum for state-level HIE efforts builds upon the facts that states serve as important organizational units and play significant roles related to health and healthcare.¹⁵ States are seeking to accommodate these roles and hopefully leverage them to advance HIE adoption and secure sustainability given the crosscutting HIE barriers, opportunities, and strategies that link local, state, and national HIE interests. Privacy and security demands have heightened state policy maker interest in potential HIE statutes and regulation, as well as strategies for oversight and monitoring. Medicaid directors see the potential to leverage Medicaid health IT to build statewide HIE capacity.

With distinct statewide cultures, resources, and politics as a backdrop, state-level HIEs demonstrate that they can serve as a mechanism to address an array of technical, legal, policy, and financial issues to serve state health policy interests. Those state-level HIEs making progress in developing and implementing data exchange show the benefits of being able incrementally to engage statewide data-sharing sources and beneficiaries; structure shared accountabilities; and balance incentives among insurers, providers, and agencies that serve the state's population.

The need for more clarity and definition about HIE form and function is growing despite its nascent stages and concerns about dampening the entrepreneurial character of HIE development. Questions now arise about how to codify a relationship between state government and an independent public-private state-level HIE to ensure formal accountability and consumer protections while continuing to support ongoing HIE capacity building.

As part of its initial 2006 work, the Project identified and described an array of distinct state-level HIE functions referred to as *building blocks*.^{16,17} Current research shows that a considerable consolidation is now evident.

Three distinct organizational functions are shown as key for building and supporting statewide interoperability while providing flexibility to accommodate an emerging multilevel HIE environment (local-state-regional-national). Organized state-level HIE efforts are coalescing around these functions as two major roles, one primary and one optional:

- **Governance**: A primary role to convene healthcare stakeholders, promote collaboration and consensus development to coordinate policies and procedures to secure data sharing, and lead and oversee statewide HIE
- **Technical Operations**: An optional and variable role in the management and operation of the technical infrastructure, services, and/or applications to support statewide HIE

¹⁵ *Development of State Level Health Information Exchange Initiatives Final Report: Extension Tasks*. AHIMA/FORE (January 23, 2007). In the interest of consumer protection, public safety, and other public purposes, states regulate (e.g., privacy laws, physician licensure, medical malpractice, insurance, and labor laws), generate information (e.g., clinical and administrative data, Medicaid, public health information, vital statistics), and channel public investments to address the needs of populations (e.g., publicly funded insurance programs like Medicaid and a variety of public health programs). States play key roles in purchasing healthcare coverage, both through Medicaid and state employee health benefit programs for which quality promotion and cost reduction are important priorities. http://www.staterhio.org/documents/FORE_Extension_Final_Report_012307_with_cover_condensed.pdf.

¹⁶ *Development of State Level Health Information Exchange Initiatives: Final Report*. AHIMA/FORE (September 1, 2006). http://www.staterhio.org/documents/Final_Report_HHSP23320064105EC_090106_000.pdf.

¹⁷ *State Level Health Information Exchanges Initiative: Development Workbook*. AHIMA/FORE (September 1, 2006). http://www.staterhio.org/documents/HHSP23320064105EC_Workbook_090106.pdf.

Figure 1 provides an overview of the functions and tasks that constitute each role that are more fully described in the Workbook.

Figure 1. Categorization of State-Level HIE Organizational Roles and Functions

Role	Governance		Technical Operations
Functions	Convene	Coordinate	Operate/Manage
Tasks	<ul style="list-style-type: none"> • Provide neutral forum for all stakeholders • Educate constituents and inform HIE policy discussions • Advocate for statewide HIE • Serve as an information resource for local HIE and health IT activities • Track/assess national HIE and health IT efforts • Facilitate consumer input 	<ul style="list-style-type: none"> • Facilitate alignment with statewide, interstate, and national HIE strategies • Promote consistency and effectiveness of statewide HIE policies and practices • Support integration of HIE efforts with other healthcare goals, objectives, and initiatives 	<ul style="list-style-type: none"> • Own or contract with vendor(s) for the hardware, software, and/or services to conduct HIE

State approaches to organizing these functions vary based on the realities of local, state, and regional healthcare environments. Although many state-level HIE initiatives plan to conduct both the governance role and technical operations, a state's technical road map for achieving statewide interoperability may or may not call for some type of centralized state-level technical functions, applications, or services.^{18,19} Distinguishing governance from technical operations supports states to define accountabilities and capacity-building strategies appropriately in relationship to state health policy and budgetary priorities, as well as the realities of state, regional, and national HIE and healthcare market characteristics. Recognition that functions are on a continuum and boundaries may blur or overlap in some cases (e.g., between functions related to coordination and technical operations) makes it conceivable that coordination activities might be delegated to a contracted technical operator overseen by a state-level HIE governance entity.

Existing state-level HIE enterprises vary in capacity and levels of maturity. However, findings indicate that many state-level HIE entities contemplate eventually taking on the role of technical operator—owning or contracting for the hardware, software, and technical capacity to facilitate health data exchange. The range of offered or proposed services includes infrastructure components (such as master person and provider indexes [MPIs], and record locator services [RLSs]) to

¹⁸ State-level HIE initiatives' missions reflect the distinction between governance and technical operations. As part of the Project, the research team assessed publicly available mission and vision statements from 21 state-level HIEs initiatives. On the basis of the use of such terms as *convene*, *inform*, *lead*, *assist*, *educate*, *guide*, and *advise*, more than 85 percent of the state-level HIE initiatives described their intentions to serve in a governance role. On the other hand, a smaller percentage of state-level HIEs, 42 percent, used terminology consistent with technical operations, including *operate*, *manage*, *design*, *build*, *develop*, and *implement*. A table of state-level HIE mission and vision statements is provided in the Workbook.

¹⁹ In Massachusetts, Michigan, and New York, for example, one entity serves as the statewide convener and coordinator, whereas other entities assume responsibilities for various elements of statewide HIE. See the Workbook for more detail.

applications (such as claims-based records, administrative data sharing, clinical messaging, eprescribing, or provision of electronic health records [EHRs] to physicians).

Appendix B provides a more detailed look at prevailing state-level technical activity.

5.1.3 Priorities for Implementing State-Level HIE Governance

Study findings confirm that an essential element of what stakeholders need and expect from a state-level HIE organization is the ability to establish and nurture a trusted, independent, and collaborative platform for education, negotiation, and decision making among diverse stakeholders, often without a history of collaboration. This state-level capacity has important implications.

- Coordination of a Statewide HIE Road Map

As part of their governance roles, state-level HIE initiatives provide coordinating functions that help align efforts and optimize resource use. State experiences demonstrate that as state-level HIE initiatives develop, additional organizational capacity is required to address the increasing policy, law, and technology complexities of HIE implementation. Among the governance coordination tasks, the creation and maintenance of a plan that delineates and prioritizes the development of the statewide HIE activity is perceived as a top priority. Often referred to as a *technical road map*, most state-level HIE initiatives develop the plans to establish milestones and time frames to calibrate efforts and track progress. The state-level HIE is widely perceived as the most appropriate entity to create and maintain a statewide road map. One representative from a local HIE effort observed, “while state government could lead and conduct the process for developing the statewide plan, stakeholders perceived the state-level HIE entity as a more objective mechanism.” A listing of state-level HIE efforts’ technical road maps is provided in the Workbook.

- Accountability, Privacy, and Security

As state-level HIE initiatives mature, governance activities typically expand. They evolve from engendering initial stakeholder engagement and collaboration to fostering the actual agreements on the framework of HIE policies and practices that will apply to ensuring appropriate data access, use, and control across the particular data-exchange participants. These may be local and statewide entities, different types of providers, and diverse data sources.

A distinct responsibility of the state-level HIE is to promote the implementation of HIE privacy and security policies and procedures to facilitate compliance with state and federal laws across diverse types of local and statewide providers and HIE entities.

Stakeholders identify coordination of privacy and security approaches as a critical priority and prominent objective for a state-level HIE governance organization.²⁰ Results from the federally sponsored HISPC project corroborate this finding: 22 of the 33 states participating in the project cited the need for a state or local coordinating body that would organize and

²⁰ *State Level Health Information Exchange: Roles in Ensuring Governance and Advancing Interoperability Preliminary Report*. AHIMA/FORE (September 28, 2007).
http://www.staterhio.org/documents/SLHIE_report_final_draft_10_16_07_print_final.pdf.

monitor electronic HIE activity, in general, and issues related to privacy and security, in particular.²¹

5.1.4 Key Elements of Effective Organizational Models

Research indicates the need for consistent and defined governance and technical operator roles that serve each state. However, the configuration of organizations providing these functions varies based on state characteristics and capacity-building strategies. HIE development continues to evolve across local, state, regional, and national medical trading areas. This development requires state-level HIEs to consider the implications of governance and technical operations that may span state boundaries.

Key observations can be made about necessary components for ensuring an effective source of state-level HIE governance and prevailing organizational models for how state-level HIE governance and technical roles are being implemented.

- Partnership: State-Level HIE and State Government

State-level HIEs have missions to serve statewide interests by making health information available to improve health and healthcare. To serve broad public policy goals, a state-level HIE strives to represent the interests of both private and public data stewards and data-sharing beneficiaries. Emerging state-level activity demonstrates the leverage that can be applied by state governments, acting in partnership with a state-level HIE governance entity, to advance strategies for HIE adoption. By empowering a single state-level HIE governance entity with recognition, accountability, and funding, state government can help to channel other resources and create incentives for participation, thereby contributing to sustainability. New York is such an example, where through state contracts, the public health agency is promoting regional HIE by making resources available, contingent upon adoption of standards and commitments for support of statewide coordination.

Previous Project recommendations highlight the importance of involving public agencies and programs in statewide data sharing as facilitated by a statewide HIE. Medicaid programs are increasingly engaged in HIE efforts through the National Association of Medicaid Directors. States like Louisiana and Arizona are examples where state HIE road maps call for building statewide capacity through Medicaid IT. However, the coordination of Medicaid HIE efforts with those of a statewide HIE governance entity is seen as increasingly relevant to achieving statewide interoperability and advancing the overall value proposition for sustainability. A state-level HIE inherently must include participation across sectors and key stakeholders. To avoid fragmentation of effort and electronic information silos, state government executive branch and agency HIE efforts can be coordinated strategies as part of a state road map and closely aligned with leadership by the state-level HIE governance entity. In this fashion, coordinated strategies can be deployed to facilitate policy support for statewide HIE development.

²¹ *Privacy and Security Solutions for Interoperable Health Information Exchange: A Nationwide Summary*, prepared by L. Dimitropoulos, RTI International for the HHS AHIC (July 2007).
http://www.hhs.gov/healthit/documents/m20070731/8a_dimitropoulos_files/800x600/slide1.html.

- Empowerment: Achieving Statewide Authority

Study informants demonstrate that an organization seeking to provide key statewide HIE roles needs distinct recognition or authority to serve in these capacities. Such empowerment is seen as important for the channeling of resources to support the sustainability of important state-level functions and to signal statewide stakeholders about the importance of engagement. States in early stages have used a variety of approaches to establish leadership to initiate state-level HIE efforts. However, distinct aspects of the state-level HIE governance role to facilitate consumer protections, compliance with federal and state laws and regulations, and best practices related to privacy and security provoke the need for more formally defined empowerment and related accountabilities.

The study reveals that state-level HIEs initiatives have employed a variety of means to establish standing as an entity or effort whose responsibilities extend statewide either temporarily or permanently. State government, charged with the regulatory and policy means to serve the interests of the state, have conferred authority to state-level HIEs by identifying them in gubernatorial executive orders, legislation, agency regulations and rules, or contracts to serve in a certain capacity or perform specified tasks (e.g., privacy assessment, technical implementation). In addition to these traditional sources of authority, a number of state-level HIE efforts have secured alternative means of recognition. Gubernatorial campaign platforms and state agency policy briefs have been used effectively to confer recognition on state-level HIE efforts. The HIE stakeholder coalitions seeking to organize a state-level initiative have in many cases solicited participation by state government representatives on state-level HIE boards. Figure 5 in Appendix C illustrates the various indices of authority for state-level HIE initiatives.

State-level HIE representatives emphasized that sources of authority and the mechanisms used to confer authority are heavily influenced by local practices and practical considerations. For example, the degree to which state governments use executive orders, rules and regulations, and contracts varies significantly from state to state and across administrations in each state. The Project Steering Committee members came to no consensus about which source or mechanism of authority was most effective across all states. However, momentum is growing to seek statutory definition of state-level HIE functions and authority. New York, Florida, and Rhode Island are examples.

- Public Private Partnership, Independent Legal Entity

Some early state-level HIE governance efforts are being led by government agencies and personnel. However, the organizational model being implemented in many cases and viewed as most viable in the long term is the state-level HIE as an independent PPP entity. This legal structure has implications for public policy. It is perceived as ultimately necessary to ensure a state-level HIE's effectiveness, including freedom from burdensome government bureaucratic and variable political agendas and constraints. A neutral independence would enable a state-level HIE to serve as a trusted and neutral source of HIE leadership and governance and to operate in an entrepreneurial role vis-à-vis building statewide HIE capacity. The Workbook provides a view of development across states.

5.2 TASK 2 FINDINGS

5.2.1 Prevailing Organization Models and Developmental Pathways

State-level HIE organizational models vary but can be categorized based on the particular roles they adopt and the nature of state government support and involvement. Although nearly all the state-level HIE initiatives studied for this Project placed themselves on trajectory toward becoming or creating an independent PPP to serve in a governance capacity, state-level HIE efforts find themselves at different places along this path.

Three prevailing organizational models can be described:

1. States in which the state government currently leads the convening and collaborating functions involving public- and private-sector interests (i.e., PPP)
2. States in which the state-level HIE initiative is an independent legal entity structured to involve public- and private-sector stakeholders (i.e., independent PPP) and is focused exclusively on the governance role
3. States in which the state-level HIE initiative is an independent PPP that focuses on both the governance and technical operations roles

Figure 2. State-Level HIE Organizational Frameworks and Functions (as of January 2008)

State	State Government-Led Collaboration (Focused on governance role)	Independent PPP (Focused on governance role)	Independent PPP (Focused on governance and technical operations)
Florida	○ →	→	
Kentucky	○		
Louisiana	○ →	→	
Tennessee	●		
Washington	○ →	→	
Massachusetts		●	
Michigan		○	
New York		○	
Arizona			○
California			○
Colorado			○
Indiana			●
Maine			○
Rhode Island			○
Utah			●

Legend ● indicates state-level HIE is currently operating as designed
 ○ indicates state-level HIE is foundational or in early implementation
 → indicates state-level HIE plans to migrate to a different organizational model

Appendix D includes profiles of state-level HIE models and case studies that highlight the dimensions of these models and the factors influencing development within particular statewide environments.

5.2.2 Sustainability Considerations

Research of the prevailing literature and discussions with key stakeholders reveals that the business models for statewide HIE remain a challenge because of the difficulties associated with developing a defensible value proposition across all HIE levels. A small number of HIE initiatives have developed sustainable operations on the basis of clear transactional efficiencies (i.e., Indiana Health Information Exchange [IHIE], New England Healthcare EDI Network [NEHEN], and Utah Health Information Network [UHIN]). Project research in 2006 corroborated the fact that offering certain types of HIE services in and of themselves can be options for state-level HIE initiatives to begin statewide HIE. Long-range sustainability models remain uncertain, in part because of the nascent stages of HIE experience. Many state-level efforts are just now poised to begin live data exchange after initial periods of capacity development. To date, no single approach or suite of state-level HIE services has yet demonstrated sustainability.²² Two key interrelated factors are identified by stakeholders as having significant bearing on long-range sustainability and must be addressed as part of HIE business models.

- Funding, the value proposition for public good functions

There is growing recognition among stakeholders that state-level HIEs provide distinct and vital public good functions. Consensus conference deliberations supported the need for a blended public-private HIE financing model that provides support for governance as a public good from all key beneficiaries, beyond relative provider sector investments in health IT capacity and data sharing. This blending is perceived as necessary to build and sustain important functions that are essential for accomplishing implementation of a statewide HIE road map. In addition to a limited set of federal grants and contracts, state governments remain the most significant investors supporting initial HIE adoption strategies. Past Project recommendations identified the importance of engaging public and private payers as participants. Across states, this remains a significant issue. Few states demonstrate ongoing business models where contributions from agencies have been quantified (e.g., Utah, Indiana), although some states are moving to define ongoing financing models (e.g., New York, Rhode Island). Momentum is building among Medicaid programs to leverage health IT strategies and resources to help build statewide HIE capacity. However, by and large, private payers are not significantly more involved in participating in state-level HIE efforts.

- Federal and state-level HIE, agenda to transform healthcare

Project observations during 2006 identified a misalignment between federal agendas for transforming healthcare (quality improvement, creating value) and advancing interoperable health information. Despite shared goals for making improved health information available,

²² *Development of State Level Health Information Exchange Initiatives Final Report: Extension Tasks*. AHIMA/FORE (January 23, 2007).

http://www.staterhio.org/documents/FORE_Extension_Final_Report_012307_with_cover_condensed.pdf

state-level HIE initiatives emphasized that separate and largely uncoordinated initiatives (e.g., patient safety organizations, Value Exchanges, data-reporting entities) threaten HIE development by creating competing demands for stakeholder involvement and resources and potentially confusing, duplicative, and otherwise misaligned organizational purposes and functions.²³ The Project Steering Committee identified the synergy between state-level HIE roles and the transformation goals and recommended greater alignment through explicitly structured mechanisms at the federal level.

Because no substantive change has occurred in federal-level action or incentives for integration of quality and HIE initiatives, updated research reveals differing strategies and levels of activity within states in achieving these objectives. Certain state-level HIE initiatives have distinguished themselves by taking clear leadership positions for coordinating quality and value initiatives. Others are taking a neutral or wait-and-see approach and plan to exist independently of the quality and value efforts in their states for some period to come.

On one hand, state-level HIEs report being preoccupied with efforts to ensure implementation and sustainability of core HIE services. On the other hand, they also relate concerns about moving into secondary use of data (e.g., for quality and performance monitoring) without sufficient foundation and support. Part of this challenge relates to the resources required to advance this type of data capacity; another is potentially derailing early stages of data sharing among their stakeholder organizations that are in the process of forging new collaborative relationships. State-level HIEs also continue to emphasize that their roles in developing HIE-related transformational capacity must be supported by explicit financing strategies that are key to building the social capital of HIE. They urge the expanded engagement of the Medicare program in making data available and structuring program incentives to leverage support for HIE development.

As more state-level HIE initiatives begin to assume technical operational roles and provide exchange services, HIE policies and practices related to data access, use, and control, especially related to secondary use of data, need to be clarified to move forward into the data stewardship roles required to support quality and value promotion.

In responding to other components of national-level HIE infrastructure development, such as HIE network certification processes and criteria, Steering Committee members emphasize the need to structure incentives for seeking such status.

5.3 BUILDING THE NETWORK OF NETWORKS

One key to state-level HIE sustainability is the ability to participate in the emerging nationwide network. Criteria for participation has yet to be defined, and the Project Steering Committee was charged with discussing the advisability of some form of accreditation for state-level and local entities that would connect to a network of networks.

²³ *Development of State Level Health Information Exchange Initiatives Final Report: Extension Tasks*. AHIMA/FORE (January 23, 2007).

http://www.staterhio.org/documents/FORE_Extension_Final_Report_012307_with_cover_condensed.pdf

Certification processes and mechanisms to measure health IT product and technical HIE specifications against standards are being developed through the work of CCHIT. Accreditation is one method used across healthcare by which performance against standards for *organizational* functions and roles related to coordinating HIE policies and practices could be overseen.

Regardless of approaches to configuring state-level HIE functions, the Steering Committee acknowledged that there must be some level of commonality across states.

- Transparency and accountability are key to consumer confidence and widespread HIE adoption, which requires that HIE roles be defined.
- HIE governance and technical operations must be provided in a reliable fashion if the benefits of widespread HIE standardization and efficiencies are to be achieved.
- Especially related to privacy and security practices, HIE entities must be appropriately defined and qualified in their ability to navigate the demands of data stewardship.

Key observations emerged from Steering Committee deliberations that support the need to define how state-level HIE organizations will participate as part of the nationwide HIE infrastructure (NHIN).

- States are beginning to act to define HIE statutory and regulatory standards and accountabilities.
- 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.
- Efforts to achieve this clarity are challenged by silos of activity that persist between different federally sponsored health IT initiatives and sector efforts. These fragmented efforts dilute the participation and support of statewide constituents.

Given that mechanisms are necessary to ensure that HIE practices are consistently and effectively implemented across widely divergent healthcare systems, the Steering Committee emphasized that reliance on a public-private model for how this HIE governance will occur 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.
- A national-level system of certification is being developed to verify the capacity of HIE products, and networks are being developed at a national level. However, 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, policy development, and organizational practices. These are functions of accreditation.
- Accreditation can accommodate the nascent stage of HIE organizational development and 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. State-level HIEs could also serve as mechanisms to oversee HIE practices in local or regional entities.

- Important lessons can be applied from the relationship and experiences of quality and accreditation that contribute to the effectiveness of this mechanism for HIE accountability. These include the value of starting small and building an iterative process that can include public input and focusing on functions that could cut across particular types of organizational definitions.

The Steering Committee advised that additional research is necessary to address key issues related to defining and structuring HIE accountabilities and oversight mechanisms in the context of the emerging NHIN interoperability infrastructure and state-level activities.

- How can a system for HIE oversight and accountability be best structured to leverage state-based statutory and regulatory authority but rely on effective self-regulatory mechanisms such as accreditation and certification?
- How do national and state-level accountability and oversight mechanisms relate to each other? How is uniformity achieved in accrediting organizations with accountabilities that may cross state lines (e.g., regional span of operations)?
- How does accreditation of HIE organizational governance functions relate to certification of products and HIE networks?
- How should the implementation of any requirements and models for HIE oversight be aligned with the timing and phases of HIE development?
- 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?

To this last point, the Steering Committee emphasized the need to link development of an accreditation structure and process to the realistic needs and expectations of the customers for this process. Issues include the timing of HIE organizational development and the presence of incentives that link to the economic viability of HIE organizations.

6 RECOMMENDATIONS

This Project has continued to study the progress and development of state-level HIE efforts over the course of almost two years. Observations from this phase of the Project point to both forward momentum and continuing challenges in advancing statewide interoperability. States are increasingly active in promoting HIE strategies and establishing HIE governance mechanisms.

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.

The following recommendations are intended to provide guidance both to emerging states and to ONC, AHIC, NHIN, and other agency HIE initiatives on the basis of the important successes among local- and state-level HIE initiatives in building viable governance and HIE services.

RECOMMENDATIONS TO STATE GOVERNMENTS AND STATEWIDE HIE STAKEHOLDERS	
State-Level HIE Governance	<p>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 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.
HIE Services, Business Models, Sustainability	<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.
Building the Nationwide Network of Networks	<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.
RECOMMENDATIONS FOR NATIONAL-LEVEL ACTION (BY AHIC, ONC, AND OTHER FEDERAL HIE INITIATIVES)	
HIE Services, Business Models, Sustainability	<ol style="list-style-type: none"> 1. Take urgent steps to define multilevel HIE value propositions and related sustainability models that will foster nationwide interoperability. <ol 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, CMS, CDC, AHRQ) work in concert. d. Actively monitor, synthesize, and disseminate findings to promote consensus building.
HIE Services, Business Models, Sustainability	<ol style="list-style-type: none"> 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. <ol 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.
Building the Nationwide Network of Networks	<ol style="list-style-type: none"> 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. <ol 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.
Building the Nationwide	<ol style="list-style-type: none"> 4. Strengthen and enhance mechanisms to promote strategic synergy between state and federal HIE agendas and initiatives.

<p>Network of Networks</p>	<ol 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. e. Support efforts to clarify and vet options for a lexicon of defined HIE terms, roles, and functions.
<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.

APPENDICES

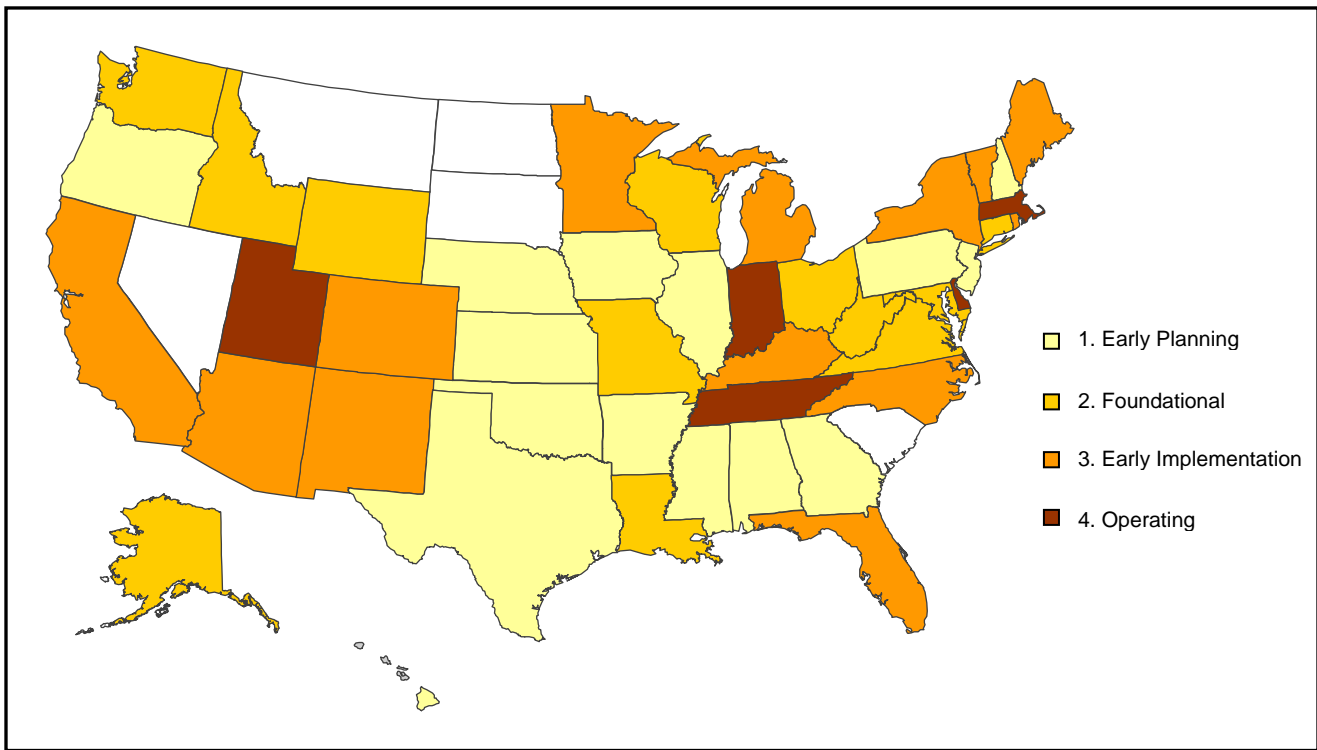
7 Appendix A - Continued Development of State-Level HIE Efforts

Although more than three-quarters of the states are pursuing HIE strategies of some kind, they vary considerably in their level of development. On the basis of a categorization developed by RTI International, state-level initiatives can be organized into the categories and development continuum described below.²⁴

1. **Early Planning (15 states as of January 2008):** An agency or government body conducted assessment of HIE efforts in the state.
2. **Foundational Component (12 states as of January 2008):** A central body was identified and established to coordinate HIE development. A governing body (e.g., board of directors) was appointed, operating committees established, and a strategic plan or road map completed.
3. **Early Implementation (13 states as of January 2008):** Some of the key road-map implementation steps have been undertaken, the state-level HIE initiative has begun coordination activities and/or selected a technology vendor, and pilot implementation has begun.
4. **Operating Implementation (five states as of January 2008):** A fully functioning state-level HIE is fulfilling either governance and/or technical operation roles, and the effort may be supporting only one or just a few types of clinical electronic HIE.

²⁴ *Privacy and Security Solutions for Interoperable Health Information Exchange: Assessment of Variation and Analysis of Solutions*. RTI International (July 2007).
http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS_0_1248_661882_0_0_18/AVAS.pdf.

Figure 3. Status of State-Level HIE Efforts (as of January 2008)



8 Appendix B - State-Level HIE Technical Operations

The research team categorized three dimensions of technical operations that could be provided by a state-level HIE:

1. *Infrastructure Components*: MPI, RLSs, clinical data repository
2. *Applications*: Administrative data sharing, clinical messaging, eprescribing, provision of EHRs
3. *Services*: Development of implementation guides, development and adoption of standards, work-flow optimization, and implementation support

Two of the state-level HIE initiatives assessed for this study are currently exchanging health information in an operational capacity; however, many states are exploring possibilities for statewide interoperability design, including how best to take advantage of economies of scale and the value created by data and transactional aggregation at both local and statewide levels.

Consistent with findings from previous studies, state-level HIE technology approaches vary considerably. The table below illustrates the types of statewide technical capacity currently offered or planned by six state-level HIE initiatives that serve in the technical operator role. *It should be noted that this information is preliminary and highly subject to change based on developing plans and timelines within these statewide HIE environments.* Additional profiles of states' technology approaches will be available in the updated Workbook.

Figure 4. State-Level HIE Technical Capacity

Technical Operations	CA CalRHIO	CO CORHIO	ME Health InfoNet	RI RIQI	TN eHealth Council	UT UHN
Infrastructure						
Statewide Master Person Index	Summer 2008	Summer 2008	Fall 2008	Summer 2008	Piloted in 2007	Summer 2009
Statewide Master Provider Index	Summer 2008	Summer 2008	Fall 2008	Summer 2008	NA	Summer 2009
Statewide Record Locator Service	Summer 2008	Summer 2008	Winter 2008	Fall 2008	TBD	Winter 2009
Central Data Repository	NA	NA	Winter 2008	NA	NA	NA
Applications						
Administrative Data Sharing	Summer 2008	TBD	NA	NA	Memphis 2006; CareSpark 2007	Already being done
Clinical Messaging	TBD	TBD	Winter 2008	TBD	TBD	2009
Credentialing	NA	NA	NA	NA	TBD	Already being done
EHR via an ASP model	TBD	NA	TBD	NA	TBD	Fall 2009

Eprescribing	Winter 2008	TBD	TBD	NA	Expansion in 2008	Fall 2009
Patient Clinical History	Summer 2008	Summer 2008	Winter 2008	Winter 2009	TBD	Fall 2009
Patient Medication History	Summer 2008	Summer 2008	Fall 2008	Winter 2009	Summer 2008	Fall 2009
Disease Management Services	NA	NA	NA	NA	Summer 2008	NA
Disease Management Registry	NA	TBD	NA	NA	Summer 2008	NA
Automated Reporting of Mandated Public Health Disease Surveillance Test Results	NA	TBD	Fall 2008	TBD	TBD	2010
Automated Reporting of Public Health Syndromic Surveillance Clinical Content	NA	TBD	NA	NA	TBD	TBD
Statewide PHR Supplier	NA	NA	NA	TBD	TBD	NA
Data Supplier to Local PHR Initiatives	Spring 2009	TBD	NA	TBD	TBD	TBD
Aggregation of Data for Marketing	NA	NA	NA	NA	NA	NA
Aggregation of Data for Public Health	NA	TBD	Spring 2011	TBD	TBD	TBD by Utah Department of Health
Aggregation of Data for Quality Metrics	NA	TBD	Spring 2011	TBD	Done at regional level	TBD
Aggregation of Data for Research	NA	TBD	NA	TBD	NA	TBD
Services						
Developing and Making Available Implementation Guides	Spring 2008	Fall 2007	Spring 2008	Fall 2008	Done at regional level	Already being done
Supporting Development and Adoption of Standards in Local HIEs		Fall 2007	Spring 2008	NA (no local HIEs)	Spring 2008	Already being done
HIE Interoperability Work-Flow Optimization Consulting	Spring 2008	NA	Summer 2008	Winter 2009		2009
Resource for Convening IT Vendors		NA	NA	NA	Summer 2008	Already being done
Clinical Data Standardization (e.g., Translation of Laboratory Test Codes to Logical Observation Identifiers Names and Codes)	Spring 2008	Spring 2008	Fall 2008	TBD	TBD	Already being done

NA – Not applicable: indicates that this feature is not envisioned as a core component of the technical framework, although this is subject to change and future development.

TBD – To be determined: indicates that this is a planned component of the technical road map, but implementation timelines have yet to be determined.

CalRHIO: California Regional Health Information Organization

CORHIO: Colorado Regional Health Information Organization

HealthInfoNet: Maine’s state-level HIE organization

RIQI: Rhode Island Quality Institute

eHealth Council: Tennessee’s state-level HIE entity

UHIN: Utah Health Information Network

9 Appendix C - Profiles of State-Level HIE: Sources and Mechanisms for Statewide Authority

State-level HIEs derive their ability to serve in a statewide capacity from a wide variety of sources. Research in 2006 revealed that launching of state-level HIE initiatives does not depend on the formation of a new legal entity.²⁵ States demonstrated that a preexisting entity can be used, or a virtual state-level HIE initiative can be established through the use of contracts and memoranda of understanding to establish the relationships between the parties or stakeholders and the governing structure for decision making.²⁶ In addition, state-level HIE initiatives frequently solicit participation of state government representatives on their boards and committees.

A state-level HIE initiative's scope of authority is commonly established by gubernatorial executive orders, legislation, agency regulations and rules, or contracts that specify performance of certain tasks (e.g., privacy assessment, technical services, standards implementation). A number of state-level HIE efforts have also used less formal mechanisms to gain recognition as entities that serve statewide interests. For example, gubernatorial campaign platforms and state agency policy briefs have been used effectively to confer recognition on state-level HIE efforts.

Figure 5 illustrates the various indices of authority for state-level HIE initiatives. It reveals a significant degree of variation across the states regarding which entities are conferred authority to provide or coordinate the elements of statewide HIE.

Although consolidating indices within a single organization has been proposed as a means for streamlining coordination efforts, some stakeholders expressed concerns about conferring control of privacy and security issues to entities that also have operational responsibilities. In its assessment of statewide HIE privacy and security approaches, the Research Triangle Institute (RTI) found that a governance arrangement in which the HIE oversees all aspects of governance could be interpreted as a conflict of interest because the HIE is responsible for making financial decisions that might conflict with its need to uphold community standards for privacy and security. For example, Vermont noted that it had observed a healthy tension between the board of directors of Vermont Information Technology Leaders, the state's HIE, and some of the proposals emerging from the state's Privacy and Security Solutions project work. The concern about the independence of the HIEs is most prevalent in states that have only a single HIE. State-level HIE efforts in Indiana, Massachusetts, and Utah, which are in more advanced stages of development, did not see an immediate need for a new governance structure.²⁷

State-level HIE representatives emphasized that sources of authority and the mechanisms used to confer authority are heavily influenced by local practices and practical considerations. For example, the degree to which state governments use executive orders, rules and regulations, and contracts varies significantly from

²⁵ *Development of State Level Health Information Exchange Initiatives: Final Report*. AHIMA/FORE (September 1, 2006). http://www.staterhio.org/documents/Final_Report_HHSP23320064105EC_090106_000.pdf.

²⁶ For an example of the multiparty data-sharing agreement and governance structure for a virtual HIE organization, see C.S. Sears et al, *The Indiana Network for Patient Care: A Case Study of a Successful Healthcare Data Sharing Agreement*. September 2005.

http://www.icemiller.com/pdf/2005_09_13_the_indiana_network_for_patient_care_a_case_study.pdf.

²⁷ Dimitropoulos, Linda. *Impact Analysis: Privacy and Security Solutions for Interoperable Health Information Exchange*. December 2007.

http://healthit.ahrq.gov/portal/server.pt/gateway/PTARGS_0_1248_815829_0_0_18/PrivacyandSecuritySolutionsProjectImpactAnalysis.pdf.

state to state. The Project Steering Committee came to no consensus about which sources or mechanisms of authority would be the most effective across all states.

Figure 5. State-Level HIE Initiatives’ Indices of Statewide Authority as of January 2008

State-Level HIE Initiatives		Authority to Serve as Governance Entity				Authority to Provide Technical Operations	
		Executive Order	Legislation	Contracts (e.g., HISPC) ²⁸	Other	Federal Contracts (AHRQ SRD) ²⁹	State Contracts (HIE Services)
AZ	Arizona Health-e Connection	●		●			●
CA	CalRHIO			●			
CO	CORHIO			●		●	
FL	HIIAB ³⁰	●	●				
IN	IHIE			●		●	●
KY	KeHN Board		●				
LA	Louisiana Health Care Quality Forum		●		●		
MA	Massachusetts Health Data Consortium			●	●		
ME	HealthInfoNet			●			●
MI	MiHIN Resource Center		●				●
NY	New York eHealth Collaborative				●		●
RI	Rhode Island Quality Institute			●	●		●
TN	Tennessee eHealth Council	●				●	
UT	UHIN				●	●	●
WA	HIIAB ³¹		●				

²⁸ In Florida, Kentucky, Louisiana, New York, Utah, and Washington, state agencies designated organizations other than the state-level HIE to lead the HISPC activities.

²⁹ AHRQ awarded State and Regional Demonstration (SRD) contracts to six states (Colorado, Delaware, Indiana, Rhode Island, Tennessee, and Utah).

³⁰ Florida’s Health Information Infrastructure Advisory Board (HIIAB) term expired in June 2007. Currently, the Agency for Health Care Administration (AHCA) is facilitating many of the statewide HIE activities.

³¹ Washington State’s HIIAB term expired in December 2006. Currently, Health Care Authority (HCA) is facilitating many of the statewide HIE activities.

10 Appendix D - Profiles of State-Level HIE: Organizational Models and Development Pathways

A. State Government–Led Public Private Partnerships

State governments play a significant role in supporting and leading state-level HIE initiatives. To date, some governors have issued executive orders, and states have passed laws to create PPPs to provide the foundational elements of convening and coordinating stakeholders. Among the Project Steering Committee members, state governments in Florida, Kentucky, Louisiana, Tennessee, and Washington illustrate a variety of leadership roles in their respective state-level HIE initiatives.

State Governments as Temporary Caretakers (Florida, Louisiana, and Washington)

In three states (Florida, Louisiana, and Washington), the originally chartered entities commissioned to study, assess, and make recommendations regarding statewide HIE have expired. To sustain statewide HIE efforts, state agencies have assumed temporary caretaker roles while planning continues for new PPPs. State government representatives from all three states indicate that they foresee their efforts eventually being advanced by independent PPP entities.

For example, after the expiration of the Florida Governor’s HIIAB three-year term in June 2007, the Office of Health Information Technology within the Florida Center for Health Information and Policy Analysis in the AHCA began sponsoring the statewide convening and coordinating functions. Currently, the Florida Center is working to create a HIE Coordinating Committee consisting of health information stakeholders to provide guidance for the development of the Florida Health Information Network.³²

In 2007 and 2008, the Florida budget to support the governance role was \$2 million. Funding was used to support four full-time staff members and coordinate and support RHIO activities through seminars, training, assistance with grant preparation, and other ad hoc tasks.

Florida’s Office of Health Information Technology	
Annual Budget	\$2 million for staff and operations
Staff	1 administrator 2 government analysts 1 government operations consultant
Services	Coordinate and support RHIO activities through seminars, training, assistance with grant preparation, and other ad hoc tasks

³² Additional details on plans for the Florida HIE Coordinating Committee are available online at http://www.fdhc.state.fl.us/SCHS/chistwg_HIECC.shtml.

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WASHINGTON (Profile of Nascent State-Led PPP)

Washington is a midsized state in terms of population (15th largest) and geographic area (20th largest). Its population of nearly 6.4 million is concentrated mainly in the urban areas of the state (82 percent), though the state has many rural parts. Approximately 15 percent of the state's population is uninsured. The provider landscape includes nearly 19,000 physicians and 393 physician groups, 111 hospitals, and 22 community health centers. Information from an informal survey conducted by the Washington State HCA and an electronic survey of members by the Washington State Medical Association in 2006 indicates that of those that responded, 25 percent of ambulatory providers, more than 50 percent of small physician offices, and 88 percent of the state's 24 largest multispecialty clinics had EHR systems.³³

Evolution of State-Level HIE Initiative: In 2005, the state of Washington legislature passed Substitute Senate Bill 5064 enacted as chapter 261, Laws of 2005. The bill required the HCA and a 12 person advisory body, the HIIAB, to develop a strategy for the adoption and use of EMRs and health ITs.

In December 2006, HCA and HIIAB jointly submitted their final report, *Washington State Health Care Authority Health Information Infrastructure: Final Report and Roadmap for State Action*, and the term of the HIIAB officially expired. The Washington State legislature and the governor adopted the report's recommendations and road map.

In 2006, the legislature appropriated \$3.4 million for the HCA and a reconstituted HIIAB to continue the work and implement the first consumer-centric health record bank (HRB) pilots to be operational by January 2009. An additional \$1 million was also appropriated to provide grants to qualifying small providers, small practices, and rural health entities of up to \$20,000.

With the a new legislative mandate, the HCA and the reconvened HIIAB are finalizing plans for a consumer-designated and -controlled HRB system to enable statewide HIE. As of this writing, HCA is vetting the details on the design, requirements, and specifications in potential pilot communities.

HIE Activities: The state of Washington enjoys significant penetration of health IT among its providers and a number of long-standing local HIE efforts including:

- ***Local HIE Efforts:*** Significant local exchange activities are occurring in Wenatchee, Tacoma, Yakima, the Tri-Cities, Bellingham, Seattle, and Spokane. Washington has two well-regarded and established HIEs: Whatcom County Health Information Network (Hi-NET) in Bellingham connects community health services, payers, hospitals, and physician offices via an Intranet, and Inland Northwest Health Services (INHS) connects Spokane-area hospitals and regional medical services.
- ***Chartered Value Exchanges:*** As of February 2008, HHS designated one entity in Washington, the Puget Sound Health Alliance, as a Chartered Value Exchange. Currently, the Puget Sound Health Alliance maintains a database of 1.6 million records covering data from 2004 to September 2006.

³³ Thomas and Associates Consulting. *Report to WA State Health Information Infrastructure Advisory Board (HIIAB) SSB 5064. March 23, 2006.* Available online at: site: <http://www.hca.wa.gov/hit/doc/HThomasHITinWAState.pdf>.

- **Administrative Data Providers:** OneHealthPort, an example of an administrative data provider created by a coalition of health plans, physicians, and hospitals, provides the Medication Information eXchange—a collaborative community-wide program to make medication history and benefit information available to healthcare providers.
- **State Registries:** Washington State maintains registries for immunization (CHILD Profile), prescription drug monitoring, HIV, and diabetes.
- **Tele-Medicine/Tele-Health:** Various communities in Washington State are collaborating with the Washington Telehealth Consortium as part of an FCC grant for a 12-month period. The consortium's goals are to leverage existing infrastructure, connect existing networks, and facilitate access to telehealth services for rural health/social service providers and residents.

Proposed Organizational Relationship: The HIIAB's final report recommended the creation of a competitive HRB model in which multiple organizations in a community operate as HRBs where consumers may choose to store their health records. According to this model, a consumer elects whether to participate and selects the HRB he or she wishes to use. A central account locator service will ultimately be established to keep track of which HRB holds the record for each consumer. When the record is needed for care, the consumer provides access information for the record (i.e., the name of his or her bank and account number). The consumer record is then obtained directly from the applicable HRB. When the care is completed, a copy of the information is sent directly to the consumer's HRB for aggregation with the existing health record.

To oversee the HRBs, representatives from the original planning process are considering the creation of an entity that would serve as a utility commission. Although still in development, the proposed utility commission would have the authority (either from legislation or rule making) to:

- Serve as a consumer ombudsman
- Accredite HRBs
- Review conformance to agreed-upon privacy, security, technical, and standards policies
- Provide for sanctions and penalties for misuse of the system
- Enforce rules

Key Findings: As in many states, the difficulty in securing adequate funds and the lack of a clear mandate for the proposed statewide HIE framework have slowed progress. Despite the setbacks, local communities continue to invest and participate in the consensus approach and work with the HCA and HIIAB to leverage community infrastructure, resources, and funding.

State Governments in Long-Term Governance Roles (Kentucky and Tennessee)

Unlike agencies in Florida, Louisiana, and Washington, state agencies in Kentucky and Tennessee are leading their respective governance roles assisted by advisory bodies consisting of local stakeholders from the public and private sectors. As these efforts continue to develop, a key challenge will be to establish an organizational structure and capacity that can span successive governors' administrations.

In Kentucky, a bifurcated governance-operator relationship is emerging between the Kentucky e-Health Network (KeHN) Board, which is an advisory committee supported by state government, and the Kentucky

e-Health Corporation (KeHC), a newly formed independent PPP. Created in March 2005, KeHC currently receives funds from the general assembly; establishes committees to set policy, procedures, and standards and issue guidance; and oversees grant programs for health IT adoption.

Although KeHC continues to serve in a governance capacity, KeHC will serve in the technical operations role. With obligations to provide quarterly financial and programmatic reports to KeHC and the state government, KeHC will manage the development and operations of the statewide KeHC, which is being supported by a \$3.75 million Medicaid Transformation Grant.³⁴

In Tennessee, Governor Phil Bredesen issued an executive order in 2006 to form Tennessee's eHealth Council, which includes public and private stakeholders from across the state, representing payers, employers, providers, and HIEs. The Council provides advice and recommendations to the governor regarding policies to support the emergence and adoption of health IT.

The Council's goal is to accelerate adoption of EHRs by building in an incremental fashion such that incremental success can build momentum. Initially, the Council's efforts were directed toward building the legal framework to forge trust and establish rules of engagement for HIE in Tennessee. Moving forward, Tennessee's road map includes milestones that will continue to strengthen the basic infrastructure hosting the Tennessee eHealth Exchange Zone. The Council collaborates among stakeholders to incubate initiatives, as well as to develop standards for HIE, including best practices, recommended minimum core data set, interoperability, and federated identity management to facilitate secure, single-sign-on capability.

In support of the Council and related projects, the State Office for eHealth Initiatives has a \$650,000 administrative budget to cover four full-time staff members, offices, overhead, meetings, supplies, and all other aspects of council administration.

Tennessee State Office for eHealth Initiatives	
Annual Budget	\$650,000 for staff, overhead, meetings, and supplies
Staff	4 full-time staff members
Services	Support for state and federal grant programs and the Governor's eHealth Council

TENNESSEE (Profile of a State Government–Led Public-Private Initiative)

Tennessee has a population of 6.1 million with more than half of the state's population residing in rural areas. Approximately 10% of Tennesseans are uninsured, and approximately one-third are enrolled in public health insurance programs.

Evolution of State-level HIE Initiative:

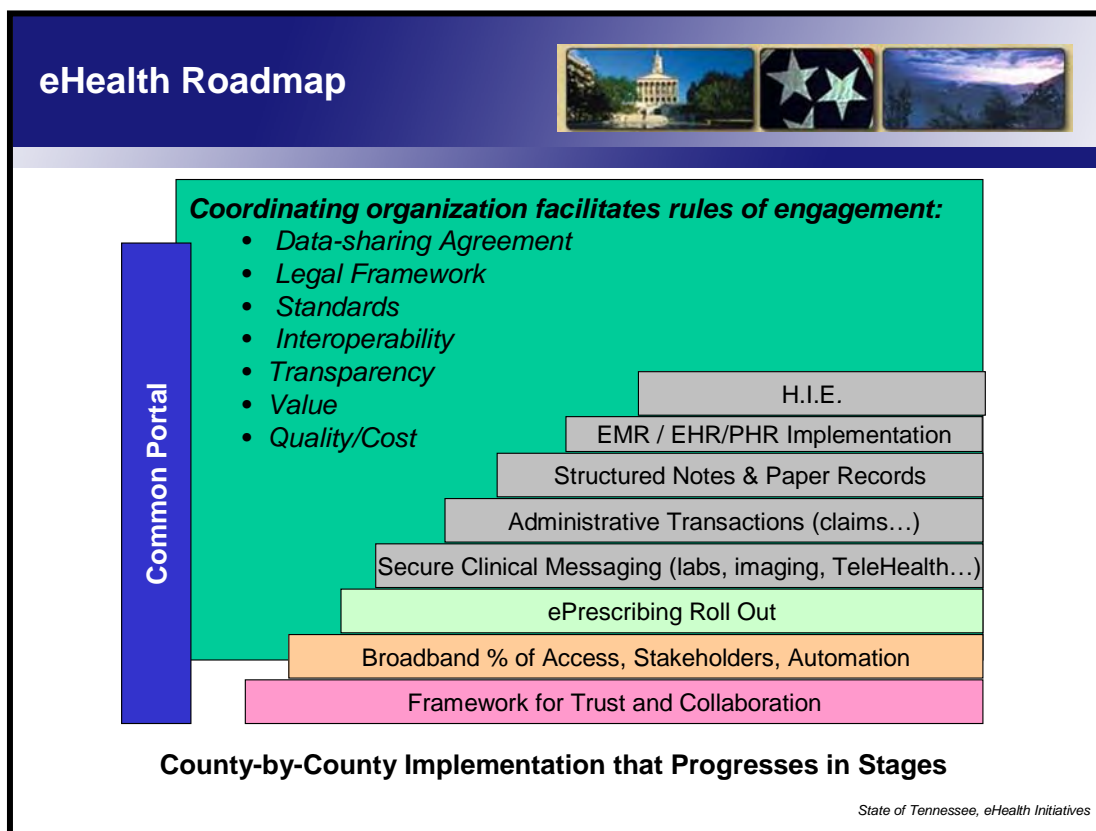
In his inaugural speech in 2003, Governor Phil Bredesen announced his intentions to reform the use of IT in healthcare. In 2004, Tennessee formally began this process when the MidSouth eHealth Alliance (MSeHA), a Memphis-area RHIO, was created with a multiyear grant of \$4.8 million federal from the AHRQ, \$7.2 million in state funding, and in-kind contributions from Vanderbilt University. MSeHA brings clinical patient encounter data from 15 area hospitals, 16 clinics, one university medical group, and one Medicaid managed care organization (MCO) to bear at the point of care. This initiative began in hospital emergency departments and has since expanded to include safety net clinics and hospitalists. MSeHA EHRs include admissions and discharge information, laboratory results, radiology results, transcriptions, and other clinical and demographic encounter

³⁴ An illustration of the organizational relationship and funding strategy for KeHC is available online at http://ehealth.ky.gov/NR/rdonlyres/DD58A179-1E6F-4815-981C-F9E15D63A86B/0/KeHC_Presentation_KeHCBusinessPlan_101607.pdf.

information. Actively sharing data since June 2006, MSeHA has 1.35 million records for 950,000 unique patients. Approximately 30,000 records are added daily.

In 2005, Tennessee’s Medicaid program, TennCare, contracted with Shared Health to provide clinical health records based on claims data for all TennCare enrollees. Sharing data among practitioners since June 2006, Shared Health has now amassed records for almost 2 million Tennesseans, or one-third of the state’s population.

In 2006, Governor Bredesen issued an executive order to form Tennessee’s eHealth Advisory Council, supported by the Office of eHealth Initiatives in the Tennessee Department of Finance and Administration. The Council includes public and private stakeholders from across the state, representing payers, employers, providers, and HIEs. Tennessee’s eHealth Council has established the following road map to guide stepwise progression toward the ultimate goal of having longitudinal EHRs for all Tennesseans.



The Council collaborates among stakeholders to develop standards for HIE including best practices, recommended minimum core data set, interoperability, and federated identity management to facilitate secure single-sign-on capability. They are also incubating initiatives to support ongoing progress and rollout strategies on multiple health IT fronts.

In 2007, eHealth Initiatives partnered with the Department of Health and the Community Health Network, using \$1.6 million in state funds and \$364,000 in United States Department of Agriculture funds, to establish the Tennessee TeleHealth Network and provide secure high-speed broadband connectivity to Tennessee’s 45 federally qualified health centers. This same team of partners also secured \$1.6 million from HRSA to develop the Middle Tennessee Rural Health Information Network connecting four rural hospitals and a community clinic for data exchange. A similar

partnership between eHealth Initiatives, the University of Tennessee Health Sciences Center, and Community Health Network secured nearly \$8 million in Federal Communications Commission (FCC) funding to connect 400 additional nonprofit sites and encourage their use of health IT and TeleHealth. The year 2007 also saw the emergence of more regional initiatives, including CareSpark in upper east Tennessee, a \$2.68 million NHIN trial implementation awardee, and the Innovation Valley Health Information Network in the Knoxville area.

In 2008, eHealth Initiatives is disbursing \$10 million in state funds to physician practices and clinics statewide to drive adoption and use of the Tennessee eHealth Exchange Zone. These grants include connectivity via the state's secure, private broadband network, as well as seed money for eprescribing or EMR applications.

HIE Activities:

- ***Local HIE Efforts:*** Three HIEs are actively exchanging data in Tennessee as of February 2008. MSeHA has 1.35 million records (clinical data) for 950,000 unique patients in the Memphis area. Shared Health has records (claims data) for almost 2 million unique Tennesseans statewide, including the Medicaid population. CareSpark is currently launching a community-based exchange that will serve 17 counties in upper east Tennessee and southwest Virginia. Emerging initiatives are under way in the Nashville area and in the upper Cumberland area of middle Tennessee.
- ***Chartered Value Exchanges:*** As of February 2008, HHS has designated one Chartered Value Exchange in Tennessee: Healthy Memphis Common Table.
- ***Statewide Data Activities:*** Built on the foundation provided by the inclusion of Tennessee's Medicaid population, Shared Health has clinical health records based primarily on claims data for almost 2 million Tennesseans, or one-third of the state's population. The Office of eHealth Initiatives is driving connectivity and eprescribing among healthcare providers statewide by disbursing grants totaling \$10 million in state funds to physician practices and clinics statewide.
- ***State Registries:*** Tennessee maintains registries for immunization, low birth weight, cancer, and controlled substances prescribed.

Organizational Relationships: The eHealth Council serves in an advisory capacity for state policy makers, recommending rules and policies to facilitate secure HIE statewide. State government is supporting the development of sufficient infrastructure to support the growth and use of the Tennessee eHealth Exchange Zone. In addition, state government is working to spur adoption of health IT to build critical mass in the marketplace.

Substantial emphasis has been placed on local control of the standards and practices for regional initiatives. The statewide rules and policies for HIE deliberately leave significant room for individual information sources to strike their own data-sharing agreements once they are connected via the common, state-facilitated infrastructure. Market forces are expected to drive further opportunities for progress once the basic infrastructure is in place for the Exchange Zone and a critical mass of users are on the system.

Key Findings: To date, the strongest drivers of statewide HIE activities in Tennessee have been gubernatorial leadership, support from the Tennessee General Assembly, highly engaged commitment from senior leadership among key stakeholders, and availability of significant state and federal funds for HIE activities.

B. Independent Public Private Partnerships: Governance

In Massachusetts, Michigan, and New York, independent PPPs have been established, and their primary focus is convening and coordinating functions. In each of the three states, the technical operations are the purview of other entities. Although the state-level HIE entities in Michigan and New York are relatively new and currently depend on state government funding to support their operations, the state-level HIE in Massachusetts has been operational since 1978 and depends on member contributions for sustainability.

In Michigan and New York, independent public-private organizations have emerged to fulfill key governance roles and help local RHIOs develop their HIE capabilities.

Launched in June 2007 from a Michigan Department of Community Health planning grant, the Michigan Health Information Network (MiHIN) Resource Center assists regional HIE efforts across the state by providing assistance and knowledge to increase the adoption rate and successful implementation. The MiHIN Resource Center's charter calls upon it to provide assistance to regional HIEs, including interpreting legal statutes; assisting with representation at state and national levels; and identifying and promoting standard policies and procedures for HIE operation, governance, and financing. MiHIN will also provide support for technological infrastructure, education, and awareness about HIE in the state and information on national initiatives and standards.³⁵

In New York, the New York e-Health Collaborative (NYeC) has emerged as the focal point for convening and coordinating statewide efforts to guide the development of a Statewide Health Information Network for New York (SHIN-NY). Incorporated in 2006, NYeC is a PPP that serves as a leader and point of convergence for healthcare stakeholders across the state to build consensus on health IT policy priorities and to collaborate on implementation efforts. The organization lists its principal goals as developing health IT and HIE policies and standards that will facilitate both interoperability and the protection of consumers' health information; evaluating and establishing accountability measures for New York's overall health IT strategy; and convening, educating, and engaging key constituencies to ensure that a broad range of stakeholders share a unified vision and approach to health IT and HIE efforts.

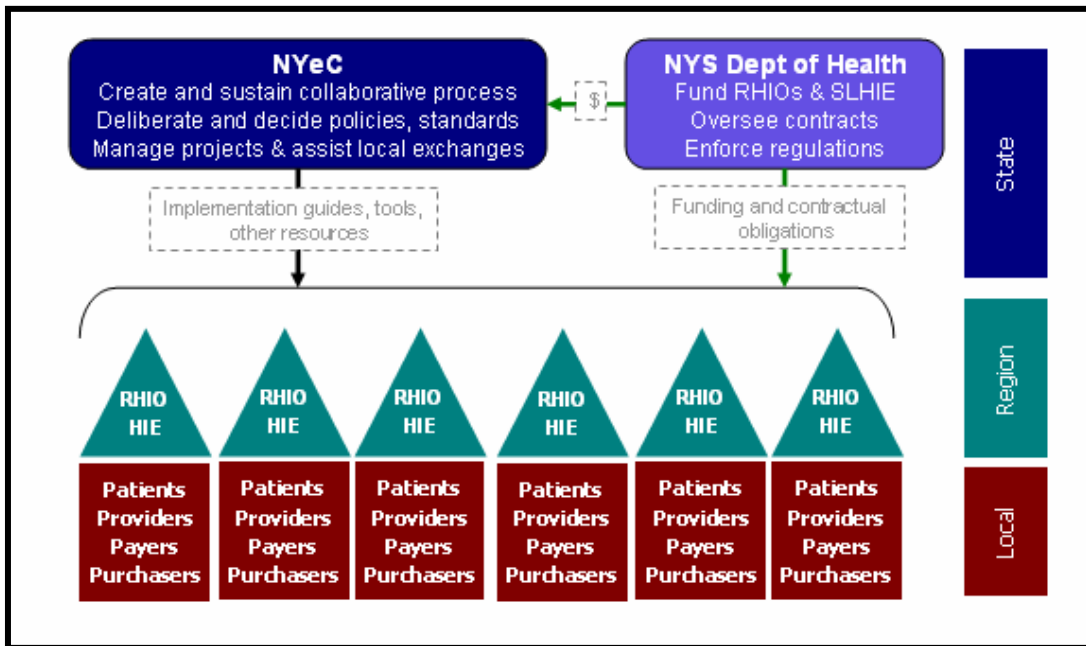
Both MiHIN and NYeC depend upon funding from state government to support staff members and convening and coordinating activities. In addition to its annual budget for staff and so on, NYeC has budgeted an additional \$150,000 for costs related to convening—meetings, conference calls, travel, and publications.

	MiHIN	NYeC
Annual Budget	\$1 million for staff	Approximately \$1.5 million for staff and costs for meetings, conference calls, travel, and publications
Staff	1 executive director 2 senior project managers 2 project managers 2 business analysts 1 analyst	1 executive director 2 program staff members focusing on communications 1 controller 2 administrative assistants

³⁵ Additional details on MiHIN and its responsibilities are online at <http://www.mihin.org>.

NEW YORK (Profile of a Nascent Independent Governance Entity)

New York’s total population is 19 million, making it the third most populous state in the United States. Nearly 8 percent of New Yorkers live in a rural area. Approximately 17 percent of New Yorkers are uninsured, and 19 percent are enrolled in public health insurance programs. Active in New York are approximately 23 commercial health maintenance organizations, 17 Medicare health maintenance organizations, and 17 Medicaid managed care plans. The provider landscape includes 236 hospitals and 131 community health centers; New York State has 21 general practitioners per 100,000 people compared with 339 specialists per 100,000. According to the Medical Society of the State of New York, the 2006 adoption rate for EHRs was 18 percent for all physicians and 8 percent for physicians in small groups or in solo practices.



Evolution of State-Level HIE Initiative: In March 2005, HHS Secretary Mike Leavitt and New York Governor George Pataki announced a reform plan for New York's Medicaid program that would include, among other focus areas, investing in eprescribing, EMRs, and RHIO activities. This waiver program is known as the Federal-State Health Reform Partnership and will reinvest \$1.5 billion of savings in federal funding for these and other purposes.

In fall 2005, the New York State Department of Health announced the availability of funds under the Health Care Efficiency and Affordability Law for New Yorkers (HEAL NY) Grant Program. HEAL NY is a multiyear, multiphased program that supports development and investment in health IT initiatives on a regional level. The HEAL NY phase 1 grant process provided \$52 million to 26 grantees for health IT and HIE efforts. HEAL NY phase 5 grants, which will provide an additional \$105 million to support RHIOs, will be released in spring 2008.

In fall 2006, NYeC was incorporated as a PPP to serve as a leader and point of convergence for healthcare stakeholders across the state to build consensus on health IT policy priorities and to collaborate on implementation efforts.

In January 2007, the Office of Health Information Technology Transformation (OHITT) was created to provide guidance to state and private-sector efforts to improve healthcare quality, accountability, and efficiency through widespread deployment of health IT. OHITT also oversees the HEAL NY grantees.

HIE Activities:

- ***Local HIE Efforts:*** By virtue of significant state funding, there are more than 20 local HIE initiatives in the state of New York, though only one, the Taconic Health Information Network and Community RHIO, was exchanging data as of February 2008.
- ***Chartered Value Exchanges:*** As of February 2008, HHS designated two entities in New York as Chartered Value Exchanges: the New York Quality Alliance and the Niagara Health Quality Coalition.
- ***Statewide Data Activities:*** New York State Department of Health manages the Electronic Medicaid Program of New York State, a database that provides Medicaid eligibility verification to service providers, Medicaid claims payments, and managed care broker enrollment.
- ***State Registries:*** New York State maintains registries for immunization, cancer, and prescription drug monitoring.

Organizational Relationships: The proposed organizational relationship of entities is articulated in the New York State Department of Health's HEAL 5 funding solicitation.³⁶

A central strategic focus of New York State's efforts is to advance interoperability through the development and implementation of a shared health information infrastructure based on a community-driven model available to all providers, payers, and patients. The HIE will evolve in two layers: a *statewide* framework of rules and policies that facilitates exchange between multiple networks at the *local* level. In this two-layer model, NYeC, with state funding, will support the creation and deployment of common policies, technical standards, and protocols, as well as regional bottom-up approaches that allow local communities to structure their own efforts on the basis of clinical and patient priorities.

At the state level, the expectation is that there will not be a single central repository or HIE. Instead, OHITT envisions the evolution of SHIN-NY, which will be responsible for a set of agreed-upon rules, policies, and standards that facilitate the flow of health information across entities.

A portion of the state's \$105 million HEAL 5 investment will be used to support the state-level activities. First, OHITT will commit \$5 million over two years to the PPP, NYeC, which will serve as a multistakeholder, consensus-driven entity that discusses, analyzes, and makes decisions regarding health information policies and standards for New York.

At the local level, RHIOs are being created to serve as the entities that govern HIE in their regions. Funds from HEAL 1 supported the creation (or expansion) of 13 RHIOs across the state. RHIOs will oversee the development of connections between local healthcare

³⁶ NY State Office of Health Information Technology Transformation. *HEAL NY Phase 5 Health IT RGA Section 7.2: Technical Discussion Document: Architectural Framework for New York's Health Information Infrastructure.*

providers and ensure they conform to the SHIN-NY policy, privacy, and technical framework.

Key Findings: To date, the following have been drivers of statewide HIE activities in New York: committed senior-level leadership in state government and key stakeholders, wide stakeholder participation, and availability of significant funds for HIE activities.

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Like those in Michigan and New York, the state-level HIE organization in Massachusetts, the Massachusetts Health Data Consortium (MHDC), is an independent PPP that fulfills the convening and coordinating functions. MHDC, formed in 1978, serves as a convening, advocacy, and policy organization. It brings the healthcare community together to address issues of common concern, holds educational events several times a year that inform stakeholders and the public about the opportunities and challenges of HIE, and helps implement projects that advance health IT and HIE, such as the Massachusetts HISPC.

As noted previously, MHDC staff members estimate that the governance role requires a 25 percent time commitment from the executive director and the director of healthcare policy. They estimate the fully loaded cost of the share of their convening activities to be approximately \$125,000 per year, spread across multiple individuals. With respect to coordination of privacy and security efforts, MHDC's level of effort to support the work of the HISPC is approximately \$500,000 per year.

The approach in Massachusetts differs from those in Michigan and New York in two ways: the sustainability model and the relationships with statewide technical operators. With respect to the former, unlike MiHIN and NYeC, MHDC's convening and coordinating functions are financed by revenue from its broad general membership, not state grants or donations. MHDC staff members commented that this financing approach promotes a sense that convening and governance are inclusive, open processes.

Massachusetts has two entities, Massachusetts Simplifying Healthcare Among Regional Entities (MA-SHARE) and NEHEN, that operate and manage various technical facets of HIE statewide. The arrangements among MHDC, MA-SHARE, and NEHEN are outlined in the profile below.

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MASSACHUSETTS³⁷ (Profile of an Established Independent Governance Entity)

Most of the 6.4 million residents of Massachusetts live in the Boston metropolitan area. Less than 1 percent of the state's population is rural. More than 1 million Massachusetts residents are enrolled in Medicaid, and nearly 970,000 are enrolled in Medicare. Most healthcare delivery is in the Boston metropolitan area, and three, large integrated delivery networks (CareGroup, Partners, and Caritas) deliver much of the healthcare for the state.

Evolution of State-Level HIE Initiative: In 1978, MHDC was founded to lead the development of a comprehensive health data system to address the health information needs of the state for the purpose of improving healthcare and health. In 1995, MHDC created the Affiliated Health Networks of New England and Chief Information Officer (CIO) Forum working groups. The CIOs from payers, providers, and employer groups agreed to meet on a monthly basis to discuss the use of IT to streamline healthcare commerce, reduce costs, and enhance care delivery processes. Early work included common privacy/security guidelines, common data sets for describing clinical encounters, and early discussions of how organizations could collectively address HIPAA compliance issues as a region rather than a series of disjointed efforts.

³⁷ Adapted from Halamka et al, *Health Care IT Collaboration in Massachusetts: The Experience of Creating Regional Connectivity* JAMIA, December 2005.

In 1998, NEHEN, a consortium of regional payers and providers, was formed to design and implement a secure electronic-commerce solution to exchange HIPAA standard transactions for eligibility, referrals, and billing. NEHEN members pay a tiered membership fee to participate in administrative data exchange. Currently, NEHEN has a greater than 90 percent adoption rate among the commercial health insurance carriers in New England.

After the creation of NEHEN, MHDC facilitated the creation of MA-SHARE. The purpose of MA-SHARE is to foster improvements in community clinical connectivity, enabling appropriate sharing of interorganizational healthcare data among the various participants in the healthcare system, including patients, clinicians, hospitals, government, and payers. Its operating goal is to serve as the clinical grid, providing community utility services that support secure clinical data exchange just as NEHEN provides administrative data exchange.

In 2003, MA-SHARE began operations as a project of MHDC. MA-SHARE promotes the interorganizational exchange of healthcare data by using information technology, standards, and administrative simplification to make accurate clinical health information available wherever needed in an efficient, cost-effective, and safe manner. MA-SHARE has received grants from stakeholders, foundations, and the federal government. To promote sustainability, MA-SHARE has initiated a subscription fee model for eprescribing (\$50,000 to \$100,000 per year, depending on size). MA-SHARE hopes to become self-sustaining in 2008.

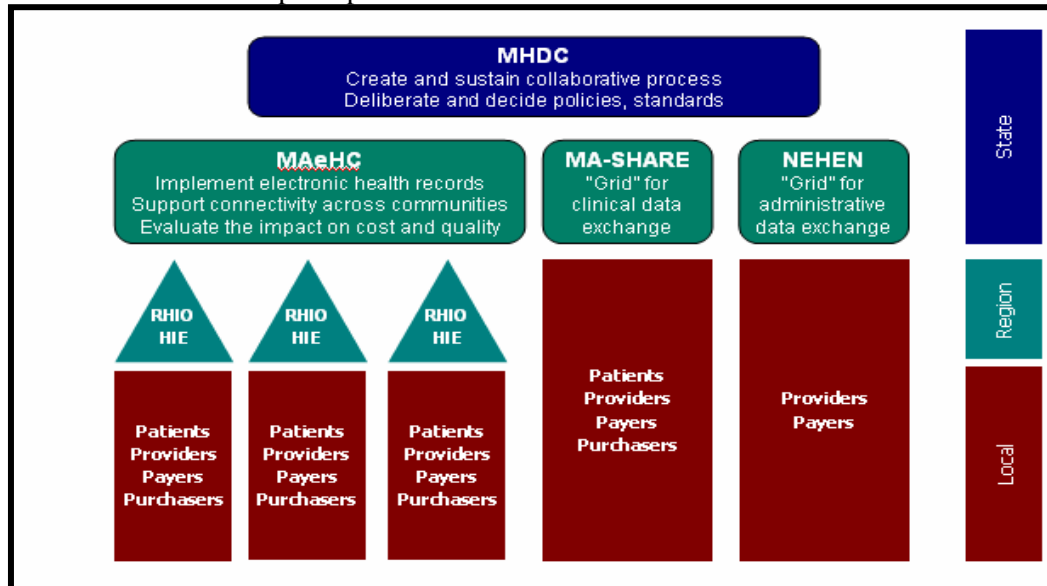
In 2004, Massachusetts e-Health Collaborative (MAeHC) formed as an initiative of the physician community to bring together the state's major healthcare stakeholders for the purpose of establishing an EHR system that would enhance the quality, efficiency, and safety of care in Massachusetts. Including 34 member organizations and participating pilot communities, MAeHC received \$50 million in initial funding from payers. MAeHC awarded \$3 million to local HIE pilot programs, on the condition that they develop self-sustaining models. MAeHC is developing a model for achieving sustainability during 2008.

HIE Activities:

- ***Local HIE Efforts:*** Massachusetts has four local HIE initiatives: one supported by the Fallon Community Health Plan and three others supported by MAeHC.
- ***Chartered Value Exchanges:*** As of February 2008, HHS designated one Massachusetts organization, the Massachusetts Chartered Value Exchange, as a Chartered Value Exchange.
- ***Statewide Data Activities:*** NEHEN serves as the grid for community exchange of administrative data, and MA-SHARE provides the grid for community exchange of clinical data.
- ***State Registries:*** Massachusetts maintains registries for prescription drug monitoring.

Organizational Relationships: Unlike other states, Massachusetts has no overarching plan for statewide HIE efforts. Instead, the governance and operational roles have evolved organically from a variety of efforts and initiatives. A clear division of labor has evolved among these organizations, with each playing a key role in accomplishing the overall objective of facilitating regional data exchange. In Massachusetts, the organizations' four separate roles have been characterized as the *convener*, the *transactor*, the *grid*, and the *last mile*. As described below, these four organizations perform these distinct but complementary

roles in a way that fully addresses the overall mission of increasing diffusion of clinical IT to improve the quality, safety, and cost-effectiveness of healthcare. Close communication and coordination across these efforts has been maintained because many of the same people are on the boards of the four principle entities.



The convening function is performed by MHDC, which brings all the stakeholders together to build relationships, share perspectives, and devise collaboration opportunities in health IT, HIE, and health data.

Actual technology development and operations, as opposed to convening, is done by MA-SHARE and NEHEN. MAeHC supports local implementation of health IT and HIE capabilities.

Although MHDC convenes the standards and policy committees, other organizations in the state (NEHEN, MA-SHARE, and MAeHC) agree to implement, test, and enforce the use of these standards and policies. For example, MAeHC will fund the installation of an EHR in a clinician’s office only if it meets the interoperability requirements specified by the technical advisory board, enabling the secure exchange of clinical data across the continuum of patient care.

Although the Massachusetts State government does not directly support local HIE activities, it participates on the board of MHDC and through the Group Insurance Commission required implementation of the Clinical Performance Improvement Initiative, which gathers quality and efficiency data for hospitals and physicians.

Key Findings: To date, the following have been drivers of statewide HIE activities in Massachusetts: long, successful history of collaboration among competitive entities; significant financial support for local HIE implementation from the private sector; independent but well-coordinated relationships with entities involved with implementation; significant nationally recognized HIE expertise at multiple levels.

C. Independent Public Private Partnerships: Governance and Technical Operations

State-Level HIE Initiatives Among Local HIEs (Arizona, California, Colorado, Indiana)

In Arizona, California, Colorado, and Indiana, state-level HIEs serve both the governance and technical operator roles and share a common challenge: they operate in geographically large and complex markets among multiple, independent HIE efforts. Moreover, in all but Indiana, the local HIEs arose before the establishment of the state-level HIE initiatives. In this environment, each must chart a technology and governance trajectory that incorporates the varied needs of their respective incumbent entities.

In Arizona, the Arizona Health-e Connection, a not-for-profit organization formed in January 2007, evolved from Governor Napolitano's 2005 executive order to develop a statewide e-health infrastructure and EHRs for every Arizonan by 2010. Arizona Health-e Connection's strategic direction has three categories: serving as an information clearinghouse on HIE, leading development of standards, and supporting infrastructure as it develops around the state. The Arizona Health-e Connection currently is focused on its governance role and trying to ensure coordination among a fledgling RHIO effort in the state, the state's Medicaid HIE, the Arizona HealthQuery (an integrated database of medical records from public and private data sources in Arizona), and local hospitals and physician practices. As part of its governance role, Arizona Health-e Connection operates a Council of Initiatives, which convenes entities in the state that are doing anything related to HIE (i.e., public health alerts, funding of rural health IT, centers of Medicaid, docket program, rural health office, etc.).

In California, the CalRHIO is a collaborative effort to incrementally build the structure and capabilities necessary for a secure statewide data-exchange system that enables California's healthcare providers and patients to access vital patient information at the time and place it is needed. On March 13, 2007, CalRHIO announced the results of its vendor selection process to build a statewide HIE utility service that will offer physicians, providers, local HIEs, government agencies, and patients access to critical information sources through a common statewide technology platform. CalRHIO is developing a business model that will permit it to raise private seed money to fund start-up costs for the CalRHIO HIE utility service, including building the statewide backbone infrastructure and integration, marketing and communication, and CalRHIO's operating budget. Financing requirements for the entire statewide implementation are estimated at \$300 million.

CORHIO began in 2004 as an informal statewide initiative after the award of a AHRQ SRD contract to Colorado through the University of Colorado Health Sciences Center. On the basis of broad stakeholder consensus, CORHIO was incorporated in early 2007 as an independent nonprofit public-partnership entity to provide statewide governance and state-level technical operations. Its initial technical development project has been to build a federated point-of-care clinical data exchange among four major Denver-based health systems, including safety net providers and Kaiser Permanente, under the terms of the AHRQ contract. The launch of live data exchange is targeted for early summer 2008, and CORHIO is in the midst of determining its business model and financing strategies to expand its technical implementation to support clinical messaging, administrative, and population data exchange in conjunction with priorities of local HIEs and other key stakeholders. CORHIO is part of Governor Bill Ritter's Building Blocks to Reform agenda; through the Colorado Department of Health Care Policy and Financing, home to Colorado Medicaid, he committed \$250,000 from the general fund to be matched by federal funds and funds to be contributed by the private sector.

The staffing models for the independent PPPs in the four states ranges from IHIE, which currently employs 32 professionals, to state-level HIE organizations that have fewer than five staff members each (Arizona Health-e Connection, CalRHIO, and CORHIO). Like many small, entrepreneurial organizations, the newer state-level HIE initiatives often rely upon external consultants and in-kind contributions of staff, space, and services from other organizations. An illustration of staffing models for state-level HIEs that combine the governance and technical operator roles is provided below.

Figure 6. Sample Staff Positions for Entities Fulfilling Governance and Technical Operations

Chief Executive Officer and President. Carries out the organization's vision and leading strategic direction. Has responsibilities for developing and executing all business plans and fundraising activities, as well as building and maintaining relationships with diverse stakeholders, both within the state and nationally.
Chief Technology Officer. Is responsible for the development and implementation of the statewide HIE service. Develops processes for and leads selection of and negotiations with vendors. Directs all implementation activities including adoption and work-flow processes.
Medical Informatics Director/Consultant. Provides clinical informatics expertise.
Chief Communications Officer. Is responsible for conceptualizing, developing, and implementing strategies to support the state-level HIE and its initiatives and functions through public, media, stakeholder, and community/consumer relations; events; marketing; Web and print publishing; brand management; grant and report writing; and presentation development.
Executive Assistant. Provides administrative support for chief executive officer and other executives and board activities. Assists with logistics for events and meetings. Manages offices and basic human resources requirements. Supports preparation of presentations, reports, other documents. Handles travel arrangements, calendars, etc.

State-Level HIE Initiatives as the Sole HIE for the State (Maine, Rhode Island, Utah)

In contrast to the states highlighted above, state-level HIE efforts in Maine, Rhode Island, and Utah operate in less populous states without the presence of local RHIOs. In essence, the state-level HIE initiatives in these three states act as the RHIOs for their entire states.

Operating in a very small state with one basic market (15 hospitals and approximately 420 practices), RIQI serves in the statewide HIE governance role and is the state's sole HIE. Incorporated in 2002, RIQI represents multiple stakeholders, including the state's Quality Improvement Organization and consumer advocates, with support from an AHRQ State and Regional Demonstration grant and additional matching funds from local stakeholders, including a five-year \$2.5 million grant from the CVS/Caremark Charitable Trust. In August 2007, the Rhode Island Department of Health, which oversees the AHRQ grant, awarded a contract to Electronic Data Systems to build the statewide HIE that RIQI will oversee. The three-year contract is valued at \$1.7 million and includes options for as many as four 12-month extensions after three years.

Once fully operational, RIQI will allocate nearly \$1 million annually for a staff that includes a chief operating officer; a privacy and security officer; a stakeholder manager; five employees addressing provider, consumer, and public relations; a four-person team addressing project management, technology, and adoption issues; and four administrative staff members.

In Utah, UHIN has served as the statewide convener and operator since 1993. UHIN, a not-for-profit, membership-owned organization currently serves all the hospitals, ambulatory surgery centers, national laboratories, and approximately 90 percent of the medical providers in Utah. UHIN's initial focus was on claims and claims-related transactions. In 1999, the UHIN board made a decision to expand and enhance its statewide network to support the electronic exchange of additional healthcare information. In 2004, UHIN received an AHRQ SRD grant to expand and enhance the current statewide UHIN gateway for the secure electronic exchange of healthcare data by using standardized transactions. The AHRQ funding has catalyzed the development of additional healthcare information exchange capabilities in Utah, and UHIN has used its existing organizational processes among community stakeholders to develop new healthcare transaction standards, many of which are clinically focused.

UHN's annual staff budget is approximately \$2.5 million for an executive director; a community project manager; a standards team of two employees; a marketing/customer services team of four employees; a project management team of four employees; and three additional staff members for accounting, human resources, and IT management services.

11 Appendix E - Bibliography

GENERAL RESOURCES AND PUBLICATIONS

AHIMA Foundation of Research and Education. *Development of State Level Health Information Exchange Initiatives, Final Report: Extension Tasks*. January 2007. Available at: http://www.staterhio.org/documents/FORE_Extension_Final_Report_012307_with_cover_condensed.pdf

AHIMA Foundation of Research and Education. *State-Level Health Information Exchange Initiative: Development Workbook*. September 2006. Available at: http://www.staterhio.org/documents/HHSP23320064105EC_Workbook_090106.pdf

Avalere Health, LLC. *Evolution of State Health Information Exchange: A Study of Visions, Strategy, and Progress*. January 2006. Available at: http://www.avalerehealth.com/research/docs/State_based_Health_Information_Exchange_Final_Report.pdf

Davis Wright Tremaine. *Sample Organization and Governance Structure*. January 2005. Available at: <https://www.dwt.com/practc/HIT/events/OrganizationandGovernanceStructure.PDF>

Dimitropoulos, Linda L. *Privacy and Security Solutions for Interoperable Health Information Exchange: Impact Analysis*. December 20, 2007. Available at: http://www.rti.org/pubs/phase2_impactanaly.pdf

National Association of State Chief Information Officers. *On the Road to RHIO: What State CIOs Need to Know*. July 2007. Available at: <http://www.nascio.org/publications/documents/NASCIO-OnTheRoadToRHIO.pdf>

National Association of State Chief Information Officers. *Profiles of Progress: State Health IT Initiatives*. November 2006. Available at: <http://www.nascio.org/publications/documents/NASCIO-ProfilesOfProgress.pdf>

National Association of State Chief Information Officers. *Profiles of Progress II: State Health IT Initiatives*. September 2007. Available at: <http://www.nascio.org/publications/documents/NASCIO-ProfilesOfProgress2.pdf>

National Governors Association Center for Best Practices. *State Alliance for e-Health: Health Information Protection Task Force Report*. August 2007. Available at: <http://www.nga.org/Files/pdf/0708EHEALTHREPORT.PDF>

National Governors Association Center for Best Practices. *State Alliance for e-Health: Health Care Practice Task Force Report*. August 2007. Available at: <http://www.nga.org/files/pdf/0708EHEALTHHCPREPORT.PDF>

National Governors Association Center for Best Practices. *State Alliance for e-Health: Health Care Practice Task Force Report*. October 2007. Available at: <http://www.nga.org/files/pdf/0710EHEALTHHCPREPORT.PDF>

National Governors Association Center for Best Practices. *State Alliance for e-Health: Health Information Communication and Data Exchange Taskforce Report*. October 2007. Available at: <http://www.nga.org/Files/pdf/0710EHEALTHHICDEREPORT.PDF>

National Conference of State Legislatures. *Critical Roles for State Legislatures in Health IT Activities Related to Health Information Exchanges*. March 2007. Available at: <http://www.ncsl.org/programs/health/forum/hitch/HITHIE.htm>

National Conference of State Legislatures. *Major Health Information Exchange Legislation, 2007: Comparison of Five State Proposals--Florida, Illinois, Indiana, Texas, Vermont*. Available at: http://www.ncsl.org/programs/health/forum/hitch/five_state.htm

National Conference of State Legislatures. *State Legislation on Health Information Exchanges and Networks: Compilation of Pending State Legislation Referring to HIE*. April 2007. Available at: http://www.ncsl.org/programs/health/forum/hitch/HIE_networks.htm

Wisconsin Public Health and Health Policy Institute. *State and Regional Experience in Health Information Collection, Sharing and Reporting. A Review of National and Regional Demonstration Projects*. February 2005. Available at: http://www.pophealth.wisc.edu/UWPHI/education/conference/health_colloquium_2005_02_07/experience.pdf

STATE GOVERNANCE MODELS AND PLANNING DOCUMENTS

Arizona

Arizona Health-e Connection. *Arizona Health-e Connection Roadmap*. April 2006. Available at: http://www.azgita.gov/tech_news/2006/Arizona%20Health%20Connection%20Roadmap.pdf

Arizona Health-e Connection. *Governance Recommendations*. September 2006. Available at: <http://workspace.ehealthinitiative.org/medigent/collaborate/view.aspx?CID=525&AID=955&AT=documents>

California

California Regional Health Information Organization. *Bylaws of CalRHIO*. Available at: <http://www.calrhio.org/docs/bylaws.pdf>

California Regional Health Information Organization. *CalRHIO: Connecting California; A Report to Stakeholders on Accomplishments and Goals*. January 2005 & 2006. Available at: http://www.calrhio.org/crweb-files/report/20060506_Stakeholder_Report.pdf

California Regional Health Information Organization. *Data Standards Roadmap Recommendations for Health Information Exchange*. April 2006. Available at: <http://www.paehi.org/Documents/Data%20Standards%20Roadmap%20Recommendations%20for%20Health%20Information%20Exchange.pdf>

California Regional Health Information Organization. *Governance Issues Survey Tool*. Available at: <http://calrhio.org/crweb-files/docs-governance/Appendix%20A%20-%20Governance%20Issues%20Survey%20Tool.pdf>

Hill, Elizabeth G. *A State Policy Approach: Promoting Health Information Technology in California*. California Legislative Analysts' Office, February 2007. Available at: http://www.lao.ca.gov/2007/health_info_tech/health_info_tech_021307.pdf

Colorado

Colorado Regional Health Information Organization (CORHIO) organizational structure, by laws. technical project. Available at www.CORHIO.org

Colorado Regional Health Information Organization (CORHIO). *Structural View of the Initiative to Develop a CORHIO: A Statewide Initiative to Build A Sustainable, Interoperable, Health Information Exchange Network*. December 2005. Available at: http://ehr.medigent.com/assets/collaborate/2006/03/02/eHI%20HRSA%20Funded%20Communitie%20SOW_2_4_CORHIO%20Structure.pdf

Florida

eHealth Initiative. *Assessment – Health Information Exchange Current Status and Future Potential in Florida*. January 2007. Available at: <http://ahca.myflorida.com/dhit/Board/FAPF20060131.pdf>

Governor's Health Information Infrastructure Advisory Board. *Final Report of the Governor's Health Information Infrastructure Advisory Board*. Available at: <http://www.fdhc.state.fl.us/dhit/Board/Brdmtg63007.pdf>

Illinois

Electronic Health Records Taskforce. *Illinois Electronic Health Records Report and Plan*. December 2006. Available at:

http://www.idph.state.il.us/ehr/f/Draft%20Report/EHR%20Taskforce%20Report_Plan%20Dec%2006.pdf

Kansas

Finnell, Chase. *State of Kansas Health Information Technology / Health Information Exchange Policy Initiative Governance Workgroup Charter*. September 2006. Available at:

<http://workspace.ehealthinitiative.org/medigent/collaborate/view.aspx?CID=461&AID=949&AT=documents>

Kentucky

The e-Health Advisory Group as presented to the Kentucky e-Health Network Board and the Cabinet for Health and Family Services. *The Kentucky e-Health Action Plan: Recommendations for Developing The Kentucky e-Health Network*. April 2007. Available at:

<http://ehealth.ky.gov/NR/rdonlyres/0AC2A0FA-86B9-40EC-AD7C-9873C7400D2C/0/eHealthActionPlan.pdf>

Matthews, Trudi L., Beaton, Benjamin, and Stout, Richard D. of the Kentucky Cabinet for Health and Family Services. *Mapping the Future of e-Health In Kentucky: The Annual Report of the Kentucky e-Health Network Board and the Kentucky Healthcare Infrastructure Authority*. October 2006. Available at: <http://ehealth.ky.gov/NR/rdonlyres/5705624F-FA77-449A-827A-FF27CDFBF2D9/0/ehealthreportnew.pdf>

Louisiana

Foundation for eHealth Initiative. *Development of RHIOs: Support of Gulf Coast Health Information Activities – Louisiana Roadmap*. April 2006.

Maine

Maine Health Information Network Technology (MHINT). *Phase II Planning and Development Report*. May – Dec 2005. Available at:

http://www.hinfonet.org/meetings/MHINT_Progress_Rpt_2005.pdf

Maine Health Information Network Technology (MHINT). *A Statewide Clinical Information Sharing Network Feasibility Study: Phase I Report*. December 2004. Available at:

<http://www.mhic.org/Phase%20I%20Report%20Draft%20121604A.pdf>

Rosen, Sharon, Passage, Casco. *A Statewide Health Information Technology Strategy to Advance Support of Quality of Care and Improved Patient Outcomes in Maine: Executive Summary Report*. June 2005. Available at: <http://www.hanleytrust.org/leadership/Ex-Summary-05.pdf>

Statewide Clinical Information Sharing System. *Vision Statement, Endorsed by MHINT Steering Committee*. October 2004. Available at:

<http://www.hinfonet.org/meetings/MHINT%20Vision%20Statement%20Endorsed%20101204.pdf>

Maryland

Task Force to Study Electronic Health Records. *Final Report: Task Force to Study EHRs*. December 31, 2007. Available online
http://mhcc.maryland.gov/electronichealth/presentations/task_force_rpt123107.pdf

Massachusetts

Halamka J, Aranow M, Ascenzo C, Bates D, Debor G, Glaser J, Goroll A, Stowe J, Tripathi M, Vineyard G. *Health Care IT Collaboration in Massachusetts: The Experience of Creating Regional Connectivity*. *Journal of the American Medical Informatics Association* 12.6 (2005) 596-601. Available at: <http://www.jamia.org/cqi/content/abstract/12/6/596>

MA-SHARE, a Program of the Massachusetts Health Data Consortium. *Program Overview and Mission Statement*. 2006. Available at: <http://www.mahealthdata.org/ma-share/mission.html>

MA-SHARE, a Program of the Massachusetts Health Data Consortium. *Rules of Order and Operating Procedures and Practices*. September 2003. Available at:
[http://ehr.medigent.com/assets/collaborate/2004/03/30/MA-SHARE%20Rules%20and%20Procedures%20\(Sept03\).pdf](http://ehr.medigent.com/assets/collaborate/2004/03/30/MA-SHARE%20Rules%20and%20Procedures%20(Sept03).pdf)

Michigan

Michigan Health Information Network (MiHIN) with Support and Assistance by the Michigan Department of Community Health and the Michigan Department of Information Technology. *Conduit to Care: Michigan's e-Health Initiative*. December 2006. Available at:
http://www.michigan.gov/documents/mihin/MiHIN_Report_Compress_v2_180321_7.pdf

Minnesota

Minnesota e-Health Initiative. *Accelerating e-Health in Minnesota: 2007 Minnesota e-Health Initiative Report to the Minnesota Legislature*. January 29, 2007. Available at:
<http://www.health.state.mn.us/e-health/legrpt2007.pdf>

Minnesota e-Health Initiative. *From Vision to Action: 2008 Minnesota e-Health Initiative Report to the Minnesota Legislature*. February 2008. Available at: <http://www.health.state.mn.us/e-health/legrpt2008.pdf>

Missouri

Missouri Healthcare Information Technology Task Force. *Missouri Healthcare Information Technology Task Force: Final Available*. September 2006. Available at:
<http://www.dhss.mo.gov/HealthInfoTaskForce/Report.pdf>

New York

The New York e-Health Collaborative (NYeC). *Implementing the HIT Stakeholder Group Planning Committee Report*. 2005. Available at: http://www.uhfnyc.org/usr_doc/NY_e-Health_Collaborative_-_Raphael.pdf

New York State Department of Health Office of Health Information Technology Transformation. *HEAL NY Phase 5 Health IT RGA Section 7.2: Technical Discussion Document: Architectural Framework for New York's Health Information Infrastructure*. October 2007.
<http://www.health.state.ny.us/technology/>

United Hospital Fund. *A Report to the New York State Department of Health: Advancing the Health Information Strategy in New York; Options and Recommendations for Creating Sustainable Multi-Stakeholder Collaboration*. November 2005. Available at: [http://www.uhfnyc.org/usr_doc/Advancing the HI Strategy 1205.pdf](http://www.uhfnyc.org/usr_doc/Advancing_the_HI_Strategy_1205.pdf)

North Carolina

North Carolina Health Care Information and Communications Alliance, Inc. *Articles of Incorporation*. April 1994. Available at: <http://www.nchica.org/>

Ohio

Health Policy Institute of Ohio. *A Strategic Roadmap and Policy Options for the Effective Adoption of Health Information Technology and Exchange in Ohio*. December 2006. Available at: <http://www.healthpolicyohio.org/pdf/HITRoadmap.pdf>

Rhode Island

Zimmerman, Amy. *Rhode Island's HIT Initiatives: A Public Private Partnership*. September 2006. Available at: <http://www.mmisconference.org/mmispresentations/Wednesday/Medicaid%20MMIS%20and%20PublicHealth/medicaid%20MMIS%20conference092706.pdf>

Tennessee

Tennessee eHealth Advisory Committee. *2007 Annual Report and Analysis*. Available at: http://www.tennesseeanytime.org/ehealth/documents/9-1-072007eHealthAnnualReport_001.pdf

Texas

Foundation for e-Health Initiative. *Health Information Exchange in Texas: Current Status and Future Potential*. July 31, 2006. Available at: http://www.hipaasolutions.org/white_papers/HIPAA%20Solutions,%20LC%20White%20Paper%20-%20eHI%20Gulf%20Coast%20Task_Texas%20Assessment_0731_06.pdf

Utah

Root, Jan. *Organizational Approaches to Establishing Community-wide Networks*. September 2005. Available at: <http://www.himss.org/Content/files/CHSC-Seminars/Root091405.ppt>

Utah Health Information Network (UHIN). *Utah Health Information Network Electronic Commerce Agreement*. Available at: <http://www.uhin.com/start/heca.htm>

Vermont

Vermont Information Technology Leaders, Inc. *Vermont Health Information Technology Plan: Strategies for Developing a Health Information Exchange Network*. July 1, 2007. Available at: <http://www.vitl.net/uploads/1184614970.pdf>

Washington

Community Database and Whatcom CMPI Project Organizational Structure. August 2004.

Available at:

<http://ehr.medigent.com/assets/collaborate/2006/03/02/eHI%20HRSA%20Funded%20Communitie%20Whatcom%20project%20definition-scope%208-04.pdf>

Washington State Health Care Authority in collaboration with the Health Information Infrastructure Advisory Board. *Washington State Health Information Infrastructure: Final Report and Roadmap for State Action*. December 2006. Available at: <http://www.hca.wa.gov/hit/doc/finalreport.pdf>

Wisconsin

The eHealth Care Quality and Patient Safety Board. *Wisconsin eHealth Action Plan: Value-based Purchasing, eHealth Technology Platform, Prevention and Disease Management and eHealth Care Quality and Patient Safety Board*. December 2006. Available at:

<http://ehealthboard.dhfs.wisconsin.gov/actionplan2006-12.pdf>

Foldy, Seth, Barthell, Edward, Pillai, Sushil. *Wisconsin Health Information Exchange (WHIE); Business Plan Summary*. December 2005. Available at:

<http://ehr.medigent.com/assets/collaborate/2006/07/12/eHI%20HRSA%20Funded%20Communitie%20WHIE%20Bus%20Plan.pdf>

Wyoming

John T. Snow, Inc. *Final Report to the Wyoming Healthcare Commission, Information Technology Technical Management Subcommittee on Developing a Wyoming Electronic Health Records Network*. November 16, 2007. Available at:

http://www.wyominghealthcarecommission.org/images/reports/11-16-07EHR_study.pdf

HIE SUSTAINABILITY AND BUSINESS MODELS PUBLICATIONS AND RESOURCES

Agency for Healthcare Research and Quality. Evidence Report/Technology Assessment, Number 132. Costs and Benefits of Health Information Technology
<http://www.ahrq.gov/downloads/pub/evidence/pdf/hitsyscosts/hitsys.pdf>

Bazzoli, Fred. *Report: RHIOs Long Way from Action*. *Healthcare IT News* (2006). Available at:
<http://www.healthcareitnews.com/story.cms?id=4644>

Bernstein, William S. *The Organization and Financing of Regional Health Information Organizations*. Manatt, Phelps and Phillips. December 2004. Available at:
http://www.ehealthinitiative.org/assets/documents/cc_dec15_2004/Tab3BernsteinOrganizationandGovernance.PPT

Blair, A. John III. *Principles and Models for the Financing and Sustainability of Health Information Networks*. December 2004. Available at:
http://www.ehealthinitiative.org/assets/documents/cc_dec15_2004/Tab4FinancingBlair.ppt

Brailer, David. *Interoperability: The Key to the Future Health Care System*. *Health Affairs: The Policy Journal of the Health Sphere*. 2005. Available at:
<http://content.healthaffairs.org/cgi/content/full/hlthaff.w5.19/DC1>

Brocht D.F., P.A. Abbott, C.A. Smith, K.A. Valus, and S.J. Berry. 1999. *A Clinic on Wheels: A Paradigm Shift in the Provision of Care and the Challenges of Information Infrastructure*. *Computers in Nursing* 17(3):109-113.

Brown, G., Eric, Holmes, J., Bradford, McEnroe, Will. *Regional Health Information Organizations' Modest Start: What's Been Built, What's Driving Progress, and When Will They Flourish?* Forrester Market Overview, 2006.

CareSpark. *Business Plan*. April 2005. Available at:
<http://ehr.medigent.com/assets/collaborate/2006/03/01/eHI%20HRSA%20Funded%20Communitie s%20CARESpark%20Business%20Plan.pdf>

Center for Health Policy and Research, University of Massachusetts Medical School. *Establishing a Foundation for Medicaid's Role in the Adoption of Health Information Technology: Opportunities, Challenges, and Considerations for the Future*. April 2007. Available at:
http://www.umassmed.edu/uploadedFiles/UMass_HIT_Report.pdf

Center for Health Transformation (CHT) and IDX Systems Corporation. *Accelerating Transformation through Health Information Technology: Summary of Findings from October 18, 2005 CHT Connectivity Conference Released November 28, 2005*. 2005. Available at:
http://www.providersedge.com/ehdocs/ehr_articles/Accelerating_Transformation_through_HIT.pdf

Colorado Health Information Exchange Business Plan. February 23, 2006.
http://www.corhio.org/docs/business/02_23_06_CORHIOBusinessPlan.doc

Colorado Health Institute. *The Promise of Health Information Technology: Improving the Quality and Cost Effectiveness of Patient Care in Colorado: White Paper*. November 2004. Available at:
www.coloradohealthinstitute.org/Documents/HIT_White_Paper.pdf

Conn, Joseph. *Destination RHIO: As Regional Data Networks Continue to Grow in Number, Some Find Financial Strength*. *Modern Healthcare* 35.42 (2005) 28-32.

Connecting for Health, Markle Foundation. *Financial, Legal and Organizational Approaches to Achieving Electronic Connectivity in Healthcare*. October 2004. Available at: http://healthcare.xml.org/resources/flo_sustain_healthcare_rpt.pdf

Connecting for Health, Markle Foundation. *Linking Health Care Information: Proposed Methods for Improving Care and Protecting Privacy, Working Group on Accurately Linking Information for Health Care Quality and Safety*. February 2005. Available at: http://www.connectingforhealth.org/assets/reports/linking_report_2_2005.pdf

Coye, Molly J., and William S. Bernstein. *Improving America's Health Care System by Investing In Information Technology*. *Health Affairs* 22.4 (2003) 56-58. Available at: <http://content.healthaffairs.org/cgi/content/full/22/4/56?ck=nck>

de Brantes, Francois, W. Emery, Douglas, Overhage, J. Marc, Glaser, John, Marchibroda, Janet. *The Potential of HIEs as Infomediaries*. *Journal of Healthcare Information Management* 21.1 69-75. Available at: <http://www.ehealthinitiative.org/assets/documents/Winter07JHIMArticle-deBrantesetal.PDF>

Deloitte Center for Health Solutions. *Health Information Exchange (HIE) Business Models: The Path to Sustainable Financial Success*. 2006. Available at: [http://www.deloitte.com/dtt/cda/doc/content/us_chs_hie-business-models_111306\(1\).pdf](http://www.deloitte.com/dtt/cda/doc/content/us_chs_hie-business-models_111306(1).pdf)

Dierker, Lynn, Davidson, Art, and Nash, Steve. A Presentation of the Colorado Health Institute. *Making the Case for a Colorado RHIO: Colorado Health Care and the Promise of HIT*. April 2006. Available at: <http://www.coloradohealthinstitute.org/documents/corhio/corhio.pdf>

eHealth Initiative and Foundation. *A Model for Estimating the Cost of HIE in a Community: Background and Technical Specifications Document*. December 2005. Available at: <http://ehr.medigent.com/assets/collaborate/2006/04/21/eHI%20cost%20model%20overview.pdf>

eHealth Initiative Foundation Report Supported by Cooperative Agreement with HRSA. *Health Information Exchange: From Start Up to Sustainability*. June 2007. Available at: http://toolkit.ehealthinitiative.org/value_creation_and_financing/eHI_HIE_Value_and_Sustainability_Release_FAQs_06.04.07_Final.pdf

Florida Agency for Health Care Administration and the Governor's Health Information Infrastructure Advisory Board. *Florida Health Information Network Architectural Considerations for State Infrastructure Draft White Paper, Version 6.2*. April 19, 2007. Available at: <http://www.fdhc.state.fl.us/dhit/Board/FWP62.pdf>

Frisse, Mark. *Lessons Learned from State and RHIOs: Organizational, Technical, and Financial Aspects*. Vanderbilt Center for Better Health. Available at: <http://www.himss.org/content/files/LessonsLearnedfromStateandRHIOs.pdf#search=%22Frisse%20Lessons%20Learned%22>

General Accounting Office, Report to the Ranking Minority Member, Committee on Health, Education, Labor, and Pensions, U.S. Senate. *Information Technology: Benefits Realized for Selected Health Care Functions*. October 2003. Available at: <http://www.gao.gov/new.items/d04224.pdf>

Glaser, John P. *The Advent of RHIO 2.0. Journal of Healthcare Information Management*. 21.3 (2007) 7-9.

Glaser, John P. *Principles and Models for the Financing and Sustainability of Health Information Networks*. Partners Healthcare. December 2004. Available at: www.ehealthinitiative.org/assets/documents/cc_dec15_2004/Tab4GlaserMAFinancing.ppt

Glitz, Rachel, and Hinckley, Gerry. *RHIO Governance Series, Part I: A Road Map for Establishing Your Health Information Organization*. Davis Wright Tremaine, LLP. February 2005. Available at: http://www.dwt.com/practc/HIT/bulletins/02-05_RHIOGovernance.htm

Gottlieb, Lawrence K., Stone, Elliot M., Stone, Diane, Dunbrack, Lynne A., and Calladine, John. *Regulatory and Policy Barriers to Effective Clinical Data Exchange: Lessons Learned from MedsInfo-ED*. *Health Affairs* 24.5 (2005) 1197-1204. Available at: <http://www.healthaffairs.org/RWJ/Gottlieb.pdf>

Halamka J, Aranow M, Ascenzo C, Bates DW, Berry K, Debor G, Fefferman J, Glaser J, Heinold J, Stanley J, Stone DL, Sullivan TE, Tripathi M, Wilkinson B. *E-Prescribing Collaboration in Massachusetts: Early Experiences from Regional Prescribing Projects*. *Journal of the American Medical Informatics Association* 13.3 (2006) 239-244.

IBM – Healthcare & Life Sciences. *Developing a Business Case for RHIO & Interoperability: Joint HL7/OMG Workshop on Interoperability among Healthcare Services Workshop*. 2005. Available at: http://www.omg.org/news/meetings/workshops/HC_2005_Proceedings/04-1M_Asthana-DuLaney.pdf

Koval, Dianne. *Real-World RHIO: A Regional Health Information Organization Blazes a Trail in Upstate New York*. *Journal of the American Health Information Management Association* 76.3 2005. 44-48. Available at: <http://ehr.medigent.com/assets/collaborate/2005/03/25/Real%20World%20RHIO.PDF>

Labkoff, Steven E., and William A. Yasnoff. *A Framework for Systematic Evaluation of Health Information Infrastructure Progress in Communities*. *Journal of Biomedical Informatics* 40.2 2007. 100-105.

Maine Health Information Center. *Maine Health Information Network Technology Phase II Planning and Development Report Part One: May-December, 2005*. January 2006. Available at: http://www.steppingupnh.org/secure/docs/MHINT_Progress_Rpt_2005.pdf

MA-Share. MA-Share Business Plan. December 2005. Available at: <http://ehr.medigent.com/assets/collaborate/2006/03/02/eHI%20HRSA%20Funded%20Communitie%202005-1220%20MA-SHARE%20Business%20Plan%202005.pdf>

MA-SHARE, MedsInfo Ed. MA-SHARE, MedsInfo-ED; Final Report. August 2005. Available at: http://www.mahealthdata.org/ma-share/projects/medsinfo/20050825_MedsInfo-ED_FinalRpt.pdf

Menachemi N., J. Burkhardt, R. Shewchuk, D. Burke, and R.G. Brooks. *Hospital Information Technology and Positive Financial Performance: A Different Approach to Finding an ROI*. *Journal of Healthcare Management* 51.1 2006. 40-59.

Mullen R., and J.T. Donnelly. *Keeping It Real--Building an ROI Model for an Ambulatory EMR Initiative that the Physician Practices Espouse*. *Journal of Healthcare Information Management* 20.1 2006. 42-52. Available at: <http://www.projectnavigation.com/pdf/ROIAmbulatoryEMR.pdf>

Ornstein S.M., L.L. MacFarlane, R.G. Jenkins, Q. Pan, and K.A. Wager. *Medication Cost Information in a Computer-Based Patient Record System: Impact on Prescribing in a Family Medicine Clinical Practice*. *Archives of Family Medicine* 8.2 1999. 118-121. Available at: <http://archfami.ama-assn.org/cgi/content/full/8/2/118>.

Pifer E.A., S. Smith, and G.W. Keever. *EMR to the Rescue: An Ambulatory Care Pilot Project Shows that Data Sharing Equals Cost Shaving*. *Healthcare Informatics* 18.2 2001. 111-114.

Remenyi, Dan. *The Elusive Nature of Delivering Benefits from IT Investment*. *Electronic Journal of Information Systems Evaluation* 3.1 2000. Available at: <http://www.ejise.com/volume-3/volume3-issue1/issue1-art1-abstract.htm>

Sutherland, Jeff. *Regional Health Information Organization (RHIO): Opportunities and Risks*. CTO PatientKeeper, Inc. November 2005. Available at: www.himss.org/Content/Files/Sutherland_RHIO_WhitePaper.pdf

Terry, Ken. *Why These Doctors Love Their RHIO*. *Medical Economics* 82.19 (2005) 8-12. Available at: <http://medicaleconomics.modernmedicine.com/memag/article/articleDetail.jsp?id=182803>

Walker, Jan, Pan, Eric, Johnston, Douglas, Adler-Milstein, Julia, W. Bates, David, and Middleton, Blackford. *The Value of Healthcare Information Exchange and Interoperability*. *Health Affairs: The Policy Journal of the Health Sphere*. 2005. Available at: <http://content.healthaffairs.org/cgi/content/full/hlthaff.w5.10/DC1>

Wild, Ellen L., T.M. Hastings, R. Gubernick, D.A. Ross, and S.N. Fehrenbach. *Key Elements for Successful Integrated Health Information Systems: Lessons from the States*. *Journal of Public Health Management and Practice*. 2005. Available at: http://www.biocrossroads.com/pdf/IHIE/05_Medical%20Economics%2010.7.05.pdf

12 Appendix F - List of Contributors and Respondents

NAME	ORGANIZATION/TITLE
Governance Considerations Interviewees	
Laura Adams, MS, RN	President and Chief Executive Officer Rhode Island Quality Institute
Antoine Agassi, BS, MBA	Director and Chair Tennessee e-Health Advisory Council
Ray Campbell, Esq, MPA	President and Chief Executive Officer Massachusetts Health Data Consortium
Dev Culver, MA	Executive Director HealthInfoNet
Don Holmquest, MD, PhD, JD	Chief Executive Officer California Regional Health Information Organization
Trudi Matthews, MA, BA	Senior Policy Advisor Kentucky Cabinet for Health and Family Services Kentucky e-Health Network Board
Beth Nagel	Health Information Technology Manager Michigan Department of Community Health
Richard K. Onizuka, PhD	Director Washington State Health Care Authority
Carol Raphael, MPA	Chair New York e-Health Collaborative
Lisa Rawlins, BS	Former Bureau Chief Center for Health Information and Policy Analysis Florida Agency for Health Care Administration
Jan Root, PhD	Executive Director Utah Health Information Network
Roxanne Townsend, MD	Deputy Director Louisiana Department of Health and Hospitals
Brad Tritle, BA	Executive Director Arizona e-Health Connection

NAME	ORGANIZATION/TITLE
Reactor Panel Participants	
Jac Davies, MPH, MS	Director of Program Development Inland Northwest Health Services
Lori Evans, MPP, MPH	Deputy Commissioner State of New York, Office of Health Information Technology Transformation
Jonah Frolich, MPH	Senior Program Officer California Health Care Foundation
Pat Hale, PhD, MD, FACP	Chief Technology Officer Adirondack Regional Community Health Information Exchange
Lonny Reisman, MD	Chief Executive Officer and Director Active Health
Alan Snell, MD, MMM	Chief Executive Officer Michiana Health Information Network
Theodore O. Will, MPA	Chief Executive Officer IPRO

NAME	ORGANIZATION/TITLE
Stakeholder Perspective Interviewees	
Juan Alaniz	Project Manager Washington State Health Care Authority
Shaun T. Alfreds, MBA, CPHIT	Policy Analyst Muskie School of Public Service, Institute for Health Policy
Tom Check	Vice President and Chief Information Officer Visiting Nurse Services of New York
Lori Evans, MPP, MPH	Deputy Commissioner State of New York, Office of Health Information Technology Transformation
John Glaser, PhD	Vice President and Chief Information Officer Partners HealthCare
Pat Hale, PhD, MD, FACP	Chief Technology Officer Adirondack Regional Community Health Information Exchange
Kevin Hutchinson	President and Chief Executive Officer SureScripts
Kevin Kearns, MBA	President and Chief Executive Officer Health Choice Network
Ken Majkowski, PharmD	Vice President, Clinical Affairs and Product Strategy RxHub
Beth Nagel, MA	Health Information Technology Manager Michigan Department of Community Health
Robert Olmed	Director of Technology Palm Beach County Community Health Alliance
Alan M. Prysunka, MD	Executive Director Maine Health Data Organization
Lynda Rudolph	Senior Pilot Executive—Brockton Massachusetts eHealth Collaborative
Margaret Stanley, MHA, BA	Executive Director Puget Sound Health Alliance
Robert Steffel, MS	Chief Executive Officer HealthBridge

13 Appendix G - Research Questionnaires

Tasks and Activities to Support the Convening Function:

Current research corroborates that *convening* is a core function for SLHIE entities and part of governance responsibilities. Informants emphasize that the ability of a SLHIE initiative to establish and nurture a trusted, independent and collaborative platform for education, negotiation and decision-making among diverse stakeholders, often without a history of collaboration, is an essential element of their obligations and their success.

Below is a list of tasks to support the *convening* function. Each task is briefly described and includes possible deliverables or “outcomes” of the activity.

For each task/service, there are questions regarding the:

- Resources required to support the task.
- Extent to which a “designated,” independent public-private partnership is likely to lead the task.
- Perceived barriers to offering the task/service.

Your responses will help us determine the costs of providing these services and the relationships with other entities that either are or could offer these services.

Instructions: Please respond to the following questions listed below. Please input your responses into the sections indicated by “Your response here...”

1. Organizational Leadership and Structure

Definition of Task: State-level HIE initiatives typically create and maintain an environment of collaborative leadership and facilitate meetings of key stakeholders across the state. State-level HIE establish committees and/or advisory structures as needed and provide mechanisms to document and disseminate activities and decisions in order to maintain transparency and encourage trust and collaboration among members. In order to support these activities, a state-level HIE effort requires the infrastructural capacity and staff to develop and maintain operational capabilities.

Example Deliverables of Task/Service: Strategic plans, operational oversight procedures, financial accountability systems, overhead and general office services, board and management activities; rosters of key stakeholders; framework for committees and advisory groups; meeting support and logistics.

A. What resources (i.e., staff, consultants, etc.) are required to maintain the basic organizational capabilities of the state-level HIE entity, advisory body, or organization? To the extent practical, please list the roles or titles of staff required to accomplish the basic convening tasks described above.

Your response here...

B. With respect to the basic organizational capabilities (i.e., staff, office space, equipment, etc.) of the state-level HIE effort in your state, who is providing funding and by what mechanisms?

Name of Organization Please identify the organization(s) providing resources or funding for general operations	Estimated Annual Amount in \$	Mechanism e.g., grant, loan, contract, in-kind services, member dues, fees for transactions
Your response here...	Your response here...	Your response here...

C. Please highlight any additional issues, challenges, or considerations in moving from an advisory body to an independent organization.

2. Track, assess & distribute information on HIE efforts *within* the State

Definition of Task: Track policy and regulations, proposed legislation/regulations, activities, and strategic direction related to HIE issues such as privacy and security (i.e., data access, use, and control) and technology considerations (i.e., standards, tools/applications, services).

Survey and maintain an inventory of local HIEs activities. Nurture relationships with local entities by understanding their capacities, procedures, governance structures and future needs. Serve as a source of information on local HIEs and their level of maturation, services offered, etc. for collaboration and shared learning opportunities. Assess the implications of developments in these areas for the state and local HIE landscape and collaboratively plan next steps strategy based on these implications.

Example Deliverables of Task/Service: Reports, fact sheets, issue briefs.

A. Have your stakeholders expressed an interest in the provision of this task/service? Please discuss.

Your response here...

B. What resources (i.e., staff, consultants, etc) and level of effort are required to perform this task?

Your response here...

C. Identify the entity (or entities) in your state that currently provide these types of services.

- | | |
|--------------------------------------|---------------------------------|
| <input type="checkbox"/> Indep SLHIE | <input type="checkbox"/> No one |
| <input type="checkbox"/> State gov't | <input type="checkbox"/> Unsure |
| <input type="checkbox"/> Other(s): | |

D. Do you envision an independent, "recognized" state-level HIE governance entity leading this task in the future?

- Yes No Unsure

E. Description of current barriers to developing this specific task as a statewide HIE function.

Your response here...

3. Track, assess and distribute information on regional and national health exchange efforts

Definition of Task: Track national policy and regulations, proposed legislation/regulations, funding opportunities, and strategic direction related to HIE issues such as privacy and security (i.e., data access, use, and control), technology considerations (i.e., standards, tools/applications, services), and quality and value efforts.

Assess the implications of developments in these areas for the state and local HIE landscape and collaboratively plan next steps strategy based on these implications. Serve as an information resource by making information collected through tracking/assessment efforts available to providers, payers, consumers and other stakeholder groups. Serve as a source of expertise for stakeholders seeking advice on health information exchange activities.

Example Deliverables of Task/Service: Reports, fact sheets, information briefs.

A. Have your stakeholders expressed an interest in the provision of this task/service? Please discuss.

Your response here...

B. What resources (i.e., staff, consultants, etc) and level of effort are required to perform this task?

Your response here...

C. Identify the entity (or entities) in your state that currently provide these types of services.

- | | |
|--------------------------------------|---------------------------------|
| <input type="checkbox"/> Indep SLHIE | <input type="checkbox"/> No one |
| <input type="checkbox"/> State gov't | <input type="checkbox"/> Unsure |
| <input type="checkbox"/> Other(s): | |

D. Do you envision an independent, "recognized" state-level HIE governance entity leading this task in the future?

- Yes No Unsure

E. Description of current barriers to developing this specific task as a statewide HIE function.

Your response here...

4. Inform policy development to advance statewide HIE

Definition of Task: Inform development of policy options. Plan and/or carry out public outreach and communication campaigns to educate stakeholders regarding the need for and benefits of electronic HIE.

Example Deliverables of Task/Service: White papers, letters of support, education and media campaigns.

A. Have your stakeholders expressed an interest in the provision of this task/service? Please discuss.

Your response here...

B. What resources (i.e., staff, consultants, etc) and level of effort are required to perform this task?

Your response here...

C. Identify the entity (or entities) in your state that currently provide these types of services.

- Indep SLHIE
- State gov't
- Other(s):
- No one
- Unsure

D. Do you envision an independent, “recognized” state-level HIE governance entity leading this task in the future?

- Yes
- No
- Unsure

E. Description of current barriers to developing this specific task as a statewide HIE function.

Your response here...

5. Advocate on behalf of local stakeholders to advance statewide HIE

Definition of Task: Provide proactive guidance to policymakers on legislation or regulations that effect HIE initiatives (i.e., white papers, letters of support, etc.). Support and/or organize public efforts to advocate on behalf of policies and legislation that support health IT and statewide HIE (create talking points for members of the public to discuss HIE with policymakers, organize petitions or letter-writing campaigns, etc.).

Example Deliverables of Task/Service: White papers, letters of support, lobbying campaigns.

A. Have your stakeholders expressed an interest in the provision of this task/service? Please discuss.

Your response here...

B. What resources (i.e., staff, consultants, etc) and level of effort are required to perform this task?

Your response here...

C. Identify the entity (or entities) in your state that currently provide these types of services.

- Indep SLHIE No one
- State gov't Unsure
- Other(s):

D. Do you envision an independent, “recognized” state-level HIE governance entity leading this task in the future?

- Yes No Unsure

E. Description of current barriers to developing this specific task as a statewide HIE function.

Your response here...

6. Facilitate consumer input

Definition of Task: Create mechanisms and procedures by which consumers can give input on health information exchange initiatives.

Example Deliverables of Task/Service: Host consumer outreach events, surveys, etc. support consumer advisory committees, resources for web enabled strategies

A. Have your stakeholders expressed an interest in the provision of this task/service? Please discuss.

Your response here...

B. What resources (i.e., staff, consultants, etc) and level of effort are required to perform this task?

Your response here...

C. Identify the entity (or entities) in your state that currently provide these types of services.

- | | |
|--------------------------------------|---------------------------------|
| <input type="checkbox"/> Indep SLHIE | <input type="checkbox"/> No one |
| <input type="checkbox"/> State gov't | <input type="checkbox"/> Unsure |
| <input type="checkbox"/> Other(s): | |

D. Do you envision an independent, "recognized" state-level HIE governance entity leading this task in the future?

- Yes No Unsure

E. Description of current barriers to developing this specific task as a statewide HIE function.

Your response here...

Tasks and Activities to Support the Coordinating Function:

State experiences demonstrate that as SLHIE initiatives develop, additional organizational capacity is required to address the various policy, legal, and technology aspects of HIE implementation. SLHIE initiatives envision an evolution in the types of convening and coordination activities they are called upon to perform: early focus is on engendering initial stakeholder collaboration, and subsequent facilitation targets the implementation of HIE policy and/or technical connections to support health information exchange.

Below is a table of tasks that includes a brief description of the activities and questions regarding:

- What entities support the task
- What resources are required to support the task (if known)
- How is or will this capacity financed (if known)

Finally, at the end of each table is a section for additional comments or comments that don't fit into the cells in the table. If you have documentation regarding the technical operations and/or business models that you are able to share, please transmit a copy via email.

Sample....

Details on State-level HIE Functions Section 2: Coordinating Function			
Tasks	Current lead in the State is....	Estimated annual funding required to support this task	How is/will this capability be financed (e.g., grants, contracts, fees, dues)
1. Technical-Roadmap Develop and maintain technical roadmap for statewide HIE	<input checked="" type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	We spent approximately \$98K over a 6 month period for a consultant to develop the tech roadmap	This was originally financed through a grant from HHS-HRSA. Updates to the roadmap will be paid for by membership dues
2. Technical-Standards Conformance Ensure that data providers and local HIEs conform to national standards for health info exchange	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input checked="" type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Don't know cost	If our SLHIE entity offers this service, we will likely seek funding from the State Dept of Health via a contract.
3. Technical-Quality of Data Establish and enforce rules for quality (i.e., accuracy,	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input checked="" type="checkbox"/> Unsure <input type="checkbox"/> Other:	Don't know cost	Unsure

Tasks	Current lead in the State is....	Estimated annual funding required to support this task	How is/will this capability be financed (e.g., grants, contracts, fees, dues)
<p>1. Technical-Roadmap Develop and maintain technical roadmap for statewide HIE</p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>
<p>2. Technical-Standards Conformance Ensure that data providers and local HIEs conform to national standards for health info exchange</p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>
<p>3. Technical-Quality of Data Establish and enforce rules for quality (i.e., accuracy, timeliness, etc.) of data exchanged statewide</p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>
<p>4. Technical-Interface Requirements Establish interface requirements for entities to participate in statewide data sharing</p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>
<p>5. Privacy-Consent Approaches Coordinate the development of <i>consent</i> approaches for statewide data exchange.</p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>
<p>6. Privacy-Disclosure & Use Policies Coordinate the development of <i>disclosure</i> and <i>use</i> of health information for statewide data exchange.</p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>
<p>7. Security-Procedures Coordinate the development of security procedures, including authentication, authorization, access control, audit, etc.</p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>

Tasks	Current lead in the State is....	Estimated annual funding required to support this task	How is/will this capability be financed (e.g., grants, contracts, fees, dues)
<p>8. Quality Initiatives Coordinate quality improvement and emerging value efforts within the state</p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>
<p>9. Transparency Support the development and operation of efforts to publicly release data regarding State providers' performance on various measures</p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>
<p>TITLE OF ADDITIONAL TASKS <i>Please describe any additional tasks that would be considered under coordination</i></p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>
<p>TITLE OF ADDITIONAL TASKS <i>Please describe any additional tasks that would be considered under coordination</i></p>	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	<p>Your response here...</p>	<p>Your response here...</p>

General Comments

Tasks and Activities to Support the Operator Role and Functions:

State-level approaches to HIE development vary based on choice of technical model for building interoperability, HIE services most in demand and feasible to implement, cultural norms, health care environments and financial and other incentives. Most SLHIE informants report that while their ultimate objective is to ensure statewide health information exchange operations, plans for how this would occur achieving this include a variety of potential technical services.

Given that existing state state-level HIE enterprises vary in capacity and levels of maturity, findings indicate that many SLHIE entities contemplate eventually taking on the role of technical operator - owning or contracting for the hardware, software, and technical capacity to facilitate health data exchange. The range of offered or proposed services includes infrastructural components (such as master person indexes, master provider indexes, and record locator services) to applications (such as claims-based records, administrative data sharing, clinical messaging, electronic prescribing, or provision of EHRs to physicians).

Each of the operational services are listed and are followed by four questions:

1. What entities support the service
2. Date of availability
3. Business plan to support service provision

Finally, at the end of each table is a section for additional comments or comments that don't fit into the cells in the table. *If you have documentation regarding the technical operations and/or business models that you are able to share, please transmit a copy via email.*

Sample...

Draft Questionnaire

Part 3: Operator Role and Technical Services

Applications Offered Statewide	Entity providing service	Date service was first or will be available	Brief description of financing plans for this task/service
Administrative Data Sharing	<input checked="" type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	1998.	Free standing, self-supporting organization funded through a tiered membership model.
Clinical Messaging	<input checked="" type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	2008.	\$425K in startup funding has been provided by sponsor organizations that expect to be service purchasers once the service is developed.
Credentialing	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input checked="" type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	No plan for statewide service.	Not Applicable
Electronic Health Record	<input checked="" type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	A local consortium is seeking to move from a 3 community pilot to a statewide rollout. This will require legislative action and is not likely for at least 6-9	The expected funding source is a 3/10 of one basis point (.003) assessment on all healthcare claims over a five year period to create a funding pool of \$500 million to support EHR adoption and usage.

Infrastructure Services	Entities providing service	Date service was first or will be available	Brief description of financing plans for this task/service
Statewide Master Person Index	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Others:	Your response here...	Your response here...
Statewide Master Provider Index	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Others:	Your response here...	Your response here...
Statewide Record Locator Service	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Others:	Your response here...	Your response here...
Clinical Data Standardization (example: translation of local lab test codes to LOINC)	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Others:	Your response here...	Your response here...
Central Data Repository	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Others:	Your response here...	Your response here...
OTHER SERVICE...	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Others:	Your response here...	Your response here...

General Comments on Infrastructure Services

“Applications”	Entity providing service	Date service was first or will be available	Brief description of financing plans for this task/service
Administrative Data Sharing	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Clinical Messaging	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Credentialing	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Electronic Health Record	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Electronic Prescribing	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Patient Clinical History	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Patient Medication History	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Disease Management Input/Tracking Service	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...

“Applications”	Entity providing service	Date service was first or will be available	Brief description of financing plans for this task/service
Disease Management Registry	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Automated Reporting of Mandated Public Health Disease Surveillance Test Results	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Automated Reporting of Public Health Syndromic Surveillance Clinical Content	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Statewide Personal Health Record (PHR) Supplier	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Data Supplier to Local Personal Health Record (PHR) Initiatives	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Aggregation of data for Marketing	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Aggregation of data for Public Health	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Aggregation of data for Quality Metrics	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...

“Applications”	Entity providing service	Date service was first or will be available	Brief description of financing plans for this task/service
Aggregation of data for Research	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
OTHER APPLICATION	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
OTHER APPLICATION	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...

General Comments

Technical Service	Entity providing service	Date service was first or will be available	Brief description of financing plans for this task/service
Develop & make available implementation guides	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Support Development and adoption of standards in local HIEs	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Health Information Exchange interoperability work flow optimization consulting	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
Resource for convening IT systems vendors to focus on developing statewide standards to support enhanced patient level exchange across products	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...
OTHER SERVICE	<input type="checkbox"/> Indep SLHIE <input type="checkbox"/> State gov't <input type="checkbox"/> No lead <input type="checkbox"/> Unsure <input type="checkbox"/> Other:	Your response here...	Your response here...

General Comments

Instructions for Ranking Convening and Coordinating Tasks:

The tables below outline the tasks and services for the *convening* and *coordinating* functions.

In each of the tables, the first column briefly describes the task.

In the second column, please rank the task based on its importance to the facilitation of health information exchange in your state. The most important task receives a “1”, the second most important a “2”, etc. There is also a space for your comments, if you choose to provide additional information.

Please assign only one ordinal number per task (i.e., don’t assign the same number to more than one task).

At the bottom of each table, there are extra rows if you would like to suggest tasks not identified in the list. You will have an opportunity to comment on each task in greater detail in the file named 2_SLHIE Roles Functions & Tasks_Details.doc.

Sample....

State-level Health Information Exchange Ranking of Convening Tasks		
Convening Tasks Brief Description	Ordinal Rank 1 = Most important	Comments, if necessary
1. Track, assess & distribute information on HIE efforts within the State Track and assess policy and regulations, proposed legislation/regulations, activities, and strategic direction related to HIE issues such as privacy and security (i.e., data access, use, and control) and technology considerations (i.e., standards, tools/applications, services). Survey and maintain an inventory of local HIEs activities. Distribute information to stakeholders.	4	
2. Track, assess and distribute information on regional and national health exchange efforts Track and assess national policy and regulations, proposed legislation/regulations, funding opportunities, and strategic direction related to HIE issues such as privacy and security (i.e., data access, use, and control), technology considerations (i.e., standards, tools/applications, services), and quality and value efforts. Distribute information to stakeholders.	1	Our stakeholders have indicated that this is a top priority for our state
3. Inform policy development to advance statewide HIE Inform development of policy options. Plan and/or carry out public outreach and communication campaigns to educate stakeholders regarding the need for and benefits of HIE.	3	
4. Advocate on behalf of local stakeholders to advance statewide HIE Provide proactive guidance to policymakers on legislation or regulations that effect HIE initiatives (i.e., white papers, letters of support, etc.). Support and/or organize public efforts to	5	While a priority, our organization's tax-exempt status prevents us from lobbying.

Convening Tasks Brief Description	Ordinal Rank 1 = Most important	Comments, if necessary
1. Track, assess & distribute information on HIE efforts within the State Track and assess policy and regulations, proposed legislation/regulations, activities, and strategic direction related to HIE issues such as privacy and security (i.e., data access, use, and control) and technology considerations (i.e., standards, tools/applications, services). Survey and maintain an inventory of local HIEs activities. Distribute information to stakeholders.		
2. Track, assess and distribute information on regional and national health exchange efforts Track and assess national policy and regulations, proposed legislation/regulations, funding opportunities, and strategic direction related to HIE issues such as privacy and security (i.e., data access, use, and control), technology considerations (i.e., standards, tools/applications, services), and quality and value efforts. Distribute information to stakeholders.		
3. Inform policy development to advance statewide HIE Inform development of policy options. Plan and/or carry out public outreach and communication campaigns to educate stakeholders regarding the need for and benefits of HIE.		
4. Advocate on behalf of local stakeholders to advance statewide HIE Provide proactive guidance to policymakers on legislation or regulations that effect HIE initiatives (i.e., white papers, letters of support, etc.). Support and/or organize public efforts to advocate on behalf of policies and legislation that support health IT and statewide HIE		
5. Facilitate consumer input Create mechanisms and procedures by which consumers can give input on health information exchange initiatives.		
x. TITLE OF ADDITIONAL TASKS <i>Please describe any additional tasks that would be considered under coordination</i>		
x. TITLE OF ADDITIONAL TASKS <i>Please describe any additional tasks that would be considered under coordination</i>		

Coordination Tasks Brief Description	Ordinal Rank 1 = Most important	Comments, if necessary
1. Technical-Roadmap Develop and maintain technical roadmap for statewide HIE		
2. Technical-Standards Conformance Ensure that data providers and local HIEs conform to national standards for health info exchange		
3. Technical-Quality of Data Establish and enforce rules for quality (i.e., accuracy, timeliness, etc.) of data exchanged statewide		
4. Technical-Interface Requirements Establish interface requirements for entities to participate in statewide data sharing		
5. Privacy-Consent Approaches Coordinate the development of <i>consent</i> approaches for statewide data exchange.		
6. Privacy-Disclosure & Use Policies Coordinate the development of <i>disclosure</i> and <i>use</i> of health information for statewide data exchange.		
7. Security-Procedures Coordinate the development of security procedures, including authentication, authorization, access control, audit, etc.		
8. Quality Initiatives Coordinate quality improvement efforts within the state. This would also include newly emerging "value" efforts.		
9. Transparency Support the development and operation of efforts to publicly release data regarding State providers' performance on various measures		
x. TITLE OF ADDITIONAL TASKS <i>Please describe any additional tasks that would be considered under coordination</i>		
x. TITLE OF ADDITIONAL TASKS <i>Please describe any additional tasks that would be considered under coordination</i>		

Instructions for Completing Technical Operations Tables:

The tables below separate the *operational* tasks into three categories: outline the tasks and services for the three primary functions of State-level HIE entities: the infrastructural components, the applications, and the technical services.

Each task is briefly described and includes a column for you to identify the importance of the technical service to facilitating health information exchange in your state. In other words, how important is the task or service for helping advance interoperability.

The ranking scale is from 0-5:

- 5= Very important
- 4= Important
- 3= Moderately important
- 2= Of little importance
- 1= Unimportant
- 0= Unsure

You will have an opportunity to comment on each task in greater detail in the 2_SLHIE Roles Functions Tasks_Details.doc file.

Technical Operations Infrastructural Technology Components/Services	Importance to facilitating HIE statewide 5= Very important 4= Important 3= Moderately important 2= Of little importance 1= Unimportant 0= Unsure
Statewide Master Person Index	Please input number (0-5) here
Statewide Master Provider Index	Please input number (0-5) here
Record Locator Service	Please input number (0-5) here
Clinical Data Standardization (example: translation of local lab test codes to LOINC)	Please input number (0-5) here
Central Data Repository	Please input number (0-5) here
TITLE OF ADDITIONAL TECHNICAL COMPONENTS <i>Please describe any additional components not mentioned in the list above.</i>	

Technical Operations Applications Offered Statewide	Importance to facilitating HIE statewide 5= Very important 4= Important 3= Moderately important 2= Of little importance 1= Unimportant 0= Unsure
Administrative Data Sharing	Please input number (0-5) here
Clinical Messaging	Please input number (0-5) here
Credentialing	Please input number (0-5) here
Electronic Health Record	Please input number (0-5) here
Electronic Prescribing	Please input number (0-5) here
Patient Clinical History	Please input number (0-5) here
Patient Medication History	Please input number (0-5) here
Disease Management Input/Tracking Service	Please input number (0-5) here
Disease Management Registry	Please input number (0-5) here
Automated Reporting of Mandated Public Health Disease Surveillance Test Results	Please input number (0-5) here
Automated Reporting of Public Health Syndromic Surveillance Clinical Content	Please input number (0-5) here
Statewide Personal Health Record (PHR) Supplier	Please input number (0-5) here
Data Supplier to Local Personal Health Record (PHR) Initiatives	Please input number (0-5) here
Aggregation of data for Marketing	Please input number (0-5) here
Aggregation of data for Public Health	Please input number (0-5) here
Aggregation of data for Quality Metrics	Please input number (0-5) here
Aggregation of data for Research	Please input number (0-5) here
TITLE OF ADDITIONAL APPLICATIONS <i>Please describe any additional applications not mentioned in the list above.</i>	
TITLE OF ADDITIONAL APPLICATIONS <i>Please describe any additional applications not mentioned in the list above.</i>	

Technical Operations Services	Importance to facilitating HIE statewide 5= Very important 4= Important 3= Moderately important 2= Of little importance 1= Unimportant 0= Unsure
Develop and make available implementation guides to help local entities participate in HIE	Please input number (0-5) here
Support Development and adoption of standards in local HIEs	Please input number (0-5) here
Health Information Exchange interoperability work flow optimization consulting	Please input number (0-5) here
Resource for Convening IT systems vendors to focus on developing statewide standards to support enhanced patient level exchange across products	Please input number (0-5) here
TITLE OF ADDITIONAL TECHNICAL SERVICES <i>Please describe any additional services not mentioned in the list above.</i>	

14 Appendix H - Rationale for Selection of States for Research Cohort

The state-level HIE initiatives that were evaluated in the first AHIMA state-level HIE report included California, Colorado, Florida, Indiana, Maine, Massachusetts, Rhode Island, Tennessee, and Utah. These nine states were chosen based on criteria such as the extent and complexity of the health data exchange under way in the state, the length of time that the initiative had been in existence, and whether the state's HIE entity was primarily organized as a single, central organization or as a coordinator of multiple local health data-sharing initiatives.

Consideration was also given to ensuring a selection of geographically diverse states that would represent all regions across the country and to selecting an adequate mix of states with both large and small geographical areas and resident populations. Finally, states were selected based on the source from which the initiative had received initial funding so that the study contained organizations that had received funds through AHRQ, ONC, and the eHealth Initiative's Connecting Communities grant program, as well as three states in which the state-level HIE initiative had not received funding from any of these primary granting entities.

In recognition of the progress other states were making, the Project team expanded the number of states in the research cohort, taking into consideration the extent to which the research cohort reflected a variety of the following characteristics:

- Maturity of state-level governance
- Extent of health information sharing within the state
- Role of state government
- Degree of financial support
- Type of governance model
- Stakeholder variety within governance structure
- Location and demographics of the state
- Degree of activity in privacy, quality, and value efforts

On the basis of these criteria, various candidate states were considered including Arizona, Delaware, Kentucky, Georgia, Louisiana, Michigan, Minnesota, New York, North Carolina, Virginia, Wisconsin, and Washington. The six states that were selected from this group to expand the diversification of state-level HIE initiatives were Arizona, Kentucky, Louisiana, Michigan, New York, and Washington.