



Development of State Level Health Information Exchange Initiatives

Final Report



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Table of Contents

1.	Acknowledgments.....	2
2.	Executive Summary	4
3.	Background, Project Goals, and Project Scope	8
3.1.	Background.....	8
3.2.	Project Goals.....	8
3.3.	Project Scope	9
4.	Project Methodology and Organization	10
4.1.	Project Methodology.....	10
4.1.1.	Literature Review and Inventory	10
4.1.2.	Identification and Selection of State-Level HIE Initiatives for Site Visits—Criteria and Process.....	11
4.1.3.	Project Team	13
4.1.4.	Interview Templates—Process and Scope of Information to Be Gathered	14
4.1.5.	Development of the Workbook.....	14
4.2.	Consensus Conference	15
4.2.1.	Purpose and Goals.....	15
4.2.2.	Attendees and Presenters	15
4.2.3.	Outcomes	16
5.	Key Findings.....	17
5.1.	Vision and Need for State-Level HIE Initiatives.....	17
5.2.	Development Process.....	17
5.3.	Role of State-Level HIE Initiatives.....	18
5.3.1.	Functions.....	18
5.3.2.	Role of State Government.....	19
5.4.	Governance	20
5.5.	Initial Funding and Financial Sustainability	20
5.5.1.	Initial Funding.....	20
5.5.2.	Financial Sustainability.....	21
5.6.	HIE Policies	22
6.	Dissemination Plan	24
7.	Conclusions and Recommendations	24
	Appendix A - Bibliography	29
	Appendix B - Project Staff Biographical Sketches	38
	Appendix C - Interview Inventory Matrix	40
	Appendix D - Public Consensus Conference Agenda	42
	Appendix E - Dissemination Channels And Talking Points	45

FINAL REPORT

Development of State-Level HIE Initiatives

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2. Executive Summary

Health information exchange (HIE) has received significant national attention recently, starting with the 2004 directive from President Bush for interoperable electronic health records (EHRs) by 2014. This was followed by the creation of the Office of the National Coordinator for Health Information Technology (ONC) and its subsequent work toward facilitating the creation of a nationwide health information network. Other activity has included the Report from the Commission on Systemic Interoperability, and federally and locally funded efforts to advance HIE throughout the country. During the past few years, more than 200 local HIE efforts have been established. More recently, a number of state-level initiatives have been formed through Executive Order, state legislation, state agency efforts, and grass roots efforts.

The purpose of this project is to gather information from existing state-level HIE initiatives to determine successful governance and legal, financial, and operational characteristics; to develop consensus on guidance for developing state-level HIE initiatives; and to disseminate these findings widely. For the purposes of this report, “state-level HIE initiative” means an HIE (which could include the exchange of clinical data, administrative data, or both) initiative or organization that is statewide in scope and involves some form of public-private collaboration, partnership, or governance.

This Final Report summarizes: (1) the project scope, methodology, and activities; (2) the key findings of the research and consensus process; (3) the plan for disseminating the results of this project; and (4) the recommendations of the Project Team on additional work that would benefit this area. The key work product from this research is the *State-Level Health Information Exchange Initiative Development Workbook*, which is publicly available in a separate document provided with this Final Report. This Workbook not only incorporates the consensus of the experts involved in this research on guiding principles but also provides practical checklists and worksheets for those considering establishing a state-level HIE initiative and which may serve to benefit local HIE efforts as well. This workbook also presents the summaries of the nine states studied in its appendices, which serve as useful case studies.

Project Scope, Methodology, and Activities

The project’s scope was to produce public domain guidance for state-level HIE initiatives. The project originally sought to identify best practices; however, because of the nascence of state-level HIE initiatives and the variability in market characteristics and practices, the focus shifted to achieving consensus on guiding principles and practical advice from the experts involved in the project and public comment. The project period was March 3, 2006 through September 1, 2006.

The project began with conducting a literature review to identify state-level HIE initiatives that met the criteria outlined in the project – specifically initiatives operating at the state-level that had an established form of public-private governance. Pursuant to the contract, a maximum of nine were selected from that list for site visits. The findings from the visits were analyzed, and a set of draft principles were prepared by project staff on the topics of role of the state-level HIE initiative (including the role of state government), governance structure, initial funding, financial sustainability, and HIE policies.

Leaders of the nine HIE initiatives served as the project's Steering Committee. Technical Advisors were also engaged to supplement the group's knowledge with specific areas of expertise in law, technology, finance, and economics. The National Conference of State Legislatures (NCSL) served as a cosponsor for the project and served in a key advisory capacity, bringing the practical perspective of state government operations and policy to light when formulating principles and options for state collaboration. For purposes of this report, the term "Project Team" references the collective group including the Steering Committee, Technical Advisors, and staff.

Through a series of conference calls and meetings, the group came to consensus on a set of principles and tools for developing state-level HIE initiatives which were presented in workbook format. The draft workbook was made publicly available on the project's Web site (www.staterhio.org), and a public Consensus Conference was held July 18-19, 2006, to seek stakeholder input on the workbook and the principles contained therein and to discuss issues facing state-level HIE initiatives. More than 130 attendees from a cross section of those interested in state-level HIE participated. They provided positive feedback on the usefulness of the workbook, and their suggestions were incorporated into the final draft of the *State-Level Health Information Exchange Initiative Development Workbook*. Summaries for each of the nine state-level HIE initiatives studied and a governing body comparison chart are provided in the Workbook's appendices.

Key Findings of the Research and Consensus Process

The information collected from the literature review and the nine site interviews indicates that most state-level HIE initiatives are still in an early stage of development, and the ones that are more mature are faced with challenges on how to expand their services in a financially sustainable way. The results also revealed that the state-level HIE initiatives differed significantly in their origins and drivers of action, state market characteristics, and approach. Rather than recommending specific practices, the Project Team focused on formulating a set of principles, checklists, and worksheets to guide the development of a state-level HIE initiative to allow it to take advantage of the particular opportunities and environment of its state. The culmination of this work is presented in detail in the *State-Level Health Information Exchange Initiative Development Workbook*. Specifically, the vision of and the need for state-level HIE initiatives is outlined, followed by detailed discussion on the recommended tasks and guiding principles for the following formative activities:

1. Assess Market Characteristics
2. Identify Champions and Key Stakeholders
3. Determine the Role of the State-Level HIE Initiative
4. Establish Governance Structure
5. Obtain Initial Funding
6. Concurrently Develop Financial Model for Sustainability, Formulate HIE Policies, and Set Up Operations and (if applicable) Technology
7. Identify Short- and Long-Term Priorities
8. Reassess Original Assumptions and Plans Often, Expect Change, and Adjust Accordingly

Dissemination Plan

The Project Team identified key audiences who would benefit from this Final Report and the *State-Level Health Information Exchange Initiative Development Workbook*, and who could be influential in encouraging application of the principles and findings to further development of state-level HIE initiatives. The broad target audiences are:

- State Government, and specifically state legislatures and governors
- Federal Government, including Congress and federal offices and agencies
- Public Health Agencies
- Providers
- Payers
- Regional HIEs
- National associations with constituents who are interested in or influential in this area
- IT vendors and consultants
- Consumer groups

A list of organizations and channels identified for reaching these audiences is detailed in Appendix E. We have identified vehicles for reaching these audiences and suggest a combination of press releases, Web distribution, utilization of Steering Committee members as a speaker's bureau, and other mechanisms to disseminate the report findings and Workbook resources.

Conclusions and Recommendations

This 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. Leaders from the nine HIE initiatives, along with other subject-matter experts, convened to reach consensus on a series of practical steps to cultivate and build sustainable statewide HIEs in concert with nationwide efforts.

The importance of state-level HIE initiatives and the roles that can only be assumed by a state-level entity were spotlighted through this work. State-level HIEs can be the bridge between communities, neighboring states, and nationwide initiatives. They can set HIE policy and standards and ensure alignment of laws and regulations. They can provide HIE services, or they can provide technical assistance and support to local entities who provide these services. They can also help catalyze health information improvements in state governmental agencies, a need that has not been widely acknowledged. State government is a stakeholder as a payer, employer, provider, regulator, and public health authority.

Analysis of findings revealed a number of barriers shared by even the most experienced state-level HIEs. Some barriers reflect the pioneering nature of this work and the challenge of building a sustainable multi-stakeholder organization. Others involve the place of the state-level HIE in nationwide health information network activities. Major barriers include:

- Securing funding for start up, organization building and to sustain organizations over time
- Lack of consensus on the most effective role for state government in HIE and lack of coordination among state agencies
- Minimal participation and support from private payers
- Non-aligned stakeholder interests
- Lack of shared experience with start up projects that produce results
- No roadmap for how state-level HIE relates to federal NHIN programs or how contiguous states should relate to one another regarding HIE.
- Informal or insufficient mechanisms for knowledge sharing among state-level organizations

Despite the need for collaborative work to address each of these barriers, the Project Team advises against any form of mandate on state-level HIEs or any action that would lock in one particular approach. A clear federal position in support of effective state-level HIE initiatives in each state would accelerate progress. This is a time for innovation and learning, but more effective channels for sharing lessons learned are needed.

The major recommendations for further research and development are summarized below. These are described more fully in *Section 7*.

1. Institute mechanisms to promote strategic synergy between state and federal HIE agendas and initiatives.
2. Identify salient financial models for sustainable HIE that state-level HIE initiatives can apply.
3. Conduct analysis to understand and leverage the role and influence of public and private payers in advancing HIE initiatives and recommend approaches for engaging payers and reducing any risk of misaligned incentives.
4. Advance understanding of how state policy makers and government can best be involved in state-level HIE initiatives by exploring public-private partnership models for state-level HIE initiatives that strike the appropriate balance of state government involvement and private sector interests to accelerate statewide HIE.
5. Develop ways to support state-level HIE initiatives and continue the work that has begun, including developing additional tools that are useful and creating a learning community and support infrastructure for continued sharing of valuable practices.

3. Background, Project Goals, and Project Scope

3.1. Background

In April 2004, President Bush issued his directive for the widespread adoption of interoperable electronic health records (EHRs) by 2014. By Executive Order, he established the Office of the National Coordinator for Health Information Technology (ONC) under the U.S. Department of Health and Human Services (HHS). Whereas the federal government has been focused on catalyzing market institutions and laying the foundation for an interoperable health information infrastructure, more than 200 local health information exchanges (HIEs, also often referred to as “regional health information organizations” or -“RHIOs,”) have formed with limited federal involvement.

On July 21, 2004, ONC released the Framework for Strategic Action, outlining the goals and strategies to realize the President’s goal. Subsequently, the Secretary of HHS initiated the next phase of the HHS health information technology (HIT) strategy. This phase is rapidly unfolding through convening leaders to coordinate public and private HIT efforts, developing strategies, contracting for studies, and funding prototypes and demonstrations to enable the infrastructure for HIE and the adoption of HIT.

A recent phenomenon is the formation of HIE initiatives at the state level with active involvement of the state government. The development of these state-level HIE initiatives is the focus of this project. At the outset of this project, the name “state-level regional health information organization” or “state-level RHIO” was used. However, through the course of this project, the Project Team came to the consensus that the use of the term “RHIO” should be avoided because it connotes different meanings to different people.

3.2. Project Goals

With the substantial increase in state-level activity around HIE through Executive Orders, legislation, and grass roots efforts across the country, the goal of this project is timely: understand the current progress of state-level HIE initiatives and develop guidance for the advancement of state-level HIE that is closely coordinated and aligned with federal initiatives. More specifically, the purpose of this project is to:

1. Identify and inventory states that have some form of public-private, state-level HIE project under development from publicly available information.
2. Select as many as nine state-level HIE initiatives that represent a variety of types of efforts and geographic regions for more extensive study and conduct on-site interviews and gather information on their governance; legal, financial, and operational characteristics; HIE policies; and short- and long-term priorities.
3. Analyze the findings to identify models and best practices.
4. Convene the leaders and subject-matter experts (including at least one public meeting) to develop consensus on guidance and recommendations for developing state-level HIE initiatives.
5. Disseminate these findings widely.

In addition to involving state-level HIE initiative leaders and some specific subject-matter experts, the Foundation of Research and Education (FORE) of the American Health Information

Management Association (AHIMA) partnered with the National Conference of State Legislatures (NCSL) to bring to the project real-world perspectives on state policy making, understanding the environment of the state health system and financing reform, and the politics and policies at the state level. These insights are incorporated into the work product of this project.

3.3. Project Scope

This project was designed to produce public domain guidance for state-level HIE efforts and to do so in a way that brings the community of these HIEs together to share successful and cost-effective practices in governing, financing, and operating state-level HIE initiatives. This project originally sought to identify best practices for state-level HIE initiatives. Best practices customarily result from measuring outcomes across time; however, initial research findings indicated that most state-level HIE initiatives are in a formative stage of development. Thus, robust outcome metrics are not yet available. In addition, the state-level HIE initiatives studied were highly variable in their structure and approach. It was clear that consensus on one single approach is not feasible at this time, and may in fact not be appropriate.

ONC desires to facilitate the sharing of practical guidance in the areas of governance, funding, operations, and HIE policies for states embarking on state-level HIE initiatives. To adjust for the early results of the research and the variability of the state landscapes, the focus of the project shifted to achieving consensus on guiding principles and practical advice, as determined by the Project Team and public comment that was offered throughout the six-month the project.

4. Project Methodology and Organization

To accomplish the five tasks in the six-month contract period, an aggressive schedule was developed. The project methodology, a description of the activities conducted and the development of the work product of this project, are described in this section.

4.1. Project Methodology

The requirements of the research project involved conducting a literature review to identify HIE efforts that were at the state level and involved some form of public-private partnership or collaboration. In this review of publicly available information, 27 states met these criteria. From that list, the project staff went through a selection process to choose nine initiatives for more in-depth examination and on-site interviews. Through discussion with ONC, the nine state-level HIE initiatives were chosen and asked to participate.

The leaders of the nine state-level HIE initiatives were invited to serve on the project's Steering Committee. In addition, Technical Advisors in different areas of expertise were engaged to assist. The NCSL representative was also considered part of the Technical Advisors group because of the particular expertise brought to bear in the area of state government and policy making. The project staff, the Steering Committee, and the Technical Advisors (collectively referred to as the "Project Team") were convened in meetings and through conference calls.

After the literature review and on-site data collection, project staff analyzed the findings, and a draft set of key elements and guiding principles were discussed at the first meeting of the Project Team. The primary work product of the Project Team is the *State-Level Health Information Exchange Initiative Development Workbook*. This Workbook presents a set of principles for the various activities involved in establishing a state-level HIE initiative, as well as other tools to aid the start-up venture.

The first version of the *State-Level Health Information Exchange Initiative Development Workbook* was released to the public through the project's Web site (www.staterhio.org) in early July 2006. A public Consensus Conference (discussed further in *Section 4.2*) was held to solicit input on the draft and to discuss issues facing the states interested in advancing statewide HIE. Those suggestions have been incorporated into version 2 of the *State-Level Health Information Exchange Initiative Development Workbook*, which is publicly available as a separate document with this Final Report.

4.1.1. Literature Review and Inventory

To identify and inventory existing HIE efforts that established a form of public-private partnership and that operate at the state-level either in a coordination or parent-organization capacity, data were gathered initially by means of literature review. Sources reviewed are listed in the bibliography in *Appendix A*. Because state-level HIE is a relatively new activity, little published research and analysis were available. The purpose of the literature review was to ensure that the project staff had a relatively comprehensive understanding of published research and coverage in the health industry press. Although there may be some activities at a state level that were not revealed in our research, this project primarily relied on the data gathered from, and direct contact with, the sample of state-level HIE initiatives that participated in the research conducted in this project. An extensive data matrix was used as a guide through site visits, phone conferences, and email communication with the nine initiatives.

4.1.2. Identification and Selection of State-Level HIE Initiatives for Site Visits—Criteria and Process

Figure 1 lists the 27 states identified as having some level of statewide HIE initiative underway in March, 2006. It must be emphasized that state-level HIE initiatives are very dynamic and organizational characteristics are continually evolving. It should also be noted that “state-level” does not necessarily imply coverage of the whole state. HIE efforts that are more comprehensive and are working toward statewide activity were included rather than efforts functioning strictly at the local community level or a region within a state. There are certainly more than 27 efforts organized in the United States, but those that did not meet the inclusion and exclusion criteria specified under this ONC contract were not studied.

The first nine state-level HIE initiatives listed in *Figure 1* and shown in green are the candidate HIE initiatives selected for site visits for this project. The nine are not organized in any particular order or priority. The next three efforts shown in orange were considered as alternates, also listed in no particular order. The remaining states identified in the literature review are also listed in *Figure 1*, again in no particular order.

The particular aspects of data sharing examined were: (1) functionality (e.g., simple versus complex, one type of application or function versus several applications) and (2) the extent of the exchange (e.g., number and variety of participants receiving and sharing data). The exchange of healthcare data was given priority when selecting the nine candidate initiatives, because achievement of the secure exchange of healthcare data for the benefit of patients and other stakeholders is the goal of any HIE effort. Thus, an initiative’s ability to facilitate and/or achieve this goal speaks of its success and would consequently qualify as a good candidate for inclusion in determining consensus on guiding principles.

Figure 1 includes a column entitled “Data Exchange.” The entry for each state is “E,” “L,” or “U.” “E” stands for extensive healthcare data sharing. “L” indicates limited data sharing (e.g., only one particular function such as medication history or only a limited number of participants sharing data). “U” means unknown to the best of our knowledge on the basis of the resources consulted. “U” is also used for HIE efforts that are still in the planning stage. That is, the HIE initiative has formulated plans to share data but for whatever reason has not actually begun sharing the data, or the extent to which they are doing so was not apparent from our review of available materials and information.

Other factors considered to ensure a variety of perspectives in the project include adequate geographic coverage indicated in the column labeled “State Location.” The regions represented are North, South, East, West, and Central. The nine initiatives selected are fairly evenly dispersed: two from the South, one from North, two from the East, three from the West, and one from the Central area. State population was considered to ensure an adequate mix of large and small states. The number of state residents could affect the complexity of the efforts to organize and implement healthcare data sharing. The population of the state was classified broadly as small, medium, or large (represented by “S,” “M,” and “L” in the State Population column). Two large states, four medium states, and three small states are represented in the mix of nine candidates. Small states have a population less than 3,000,000. Medium states have a population greater than 3,000,000, but less than 10,000,000. Large states are therefore more than 10,000,000 in population. Population figures were based on U.S. Census Bureau statistics from July 2004.

The column labeled “M vs. U” indicates whether the effort is organized as a single, central organization for health data sharing (represented by “U”) or an organization that is coordinating multiple local health data-sharing efforts in different regions of its state (represented by “M”). This information was used to ensure that the nine initiatives selected included some “M” and some “U” to be able to understand and represent differing approaches during the consensus-building process.

Longevity was also considered an important factor. Even if the effort was not yet exchanging healthcare data, the fact that it had been in existence and making efforts to organize such data sharing across some period of time was valuable. The effort could provide useful input on guiding principles on the basis of some of the barriers experienced. Because extensive information was not necessarily available for each effort, the “Duration” column simply indicates whether the HIE effort was formed within the past two years or had been in existence for a longer time.

Activities that focused primarily on telemedicine or telehealth or the adoption of electronic medical records were not included in the inventory process, because they were not within the scope of this project. Such an initiative would not be a good candidate for identifying guiding principles as required in this project, because it likely would not have the same broader goal of sharing different kinds of healthcare data across disparate systems and would not face the same challenges.

Figure 1. State-Level HIE Initiative Candidates

	State	Data Exchange (E, L, U)	M vs. U	State Location (N,S,E,W,C)	State Population (S,M,L)	Duration (≤ 2yrs vs. > 2yrs)
1	CA	L	M	W	L	≤ 2yrs
2	CO	L	M	W	M	≤ 2yrs
3	RI	U	U	E	S	≤ 2yrs
4	FL	U	U	S	L	≤ 2yrs
5	IN	E	U	C	M	> 2yrs
6	UT	U	U	W	S	> 2yrs
7	MA	L	U	E	M	> 2yrs
8	ME	U	U	N	S	> 2yrs
9	TN	U	M	S	M	≤ 2yrs
10	DE	U	U	E	S	> 2yrs
11	NC	U	U	S	M	> 2yrs
12	WI	U	U	C	M	> 2yrs
13	NY	U	?	E	L	≤ 2yrs
14	WV	U	U	E	S	≤ 2yrs
15	AZ	U	U	W	M	≤ 2yrs
16	MD	U	U	E	M	≤ 2yrs
17	VA	U	U	E	M	≤ 2yrs
18	HI	U	U	W	S	≤ 2yrs
19	MI	U	U	C	L	≤ 2yrs
20	MN	U	U	C	M	≤ 2yrs
21	NM	U	U	W	S	≤ 2yrs
22	NE	U	U	C	S	≤ 2yrs
23	KY	U	U	C	M	> 2yrs
24	WY	U	U	W	S	≥ 2yrs
25	PA	U	M	E	L	≤ 2yrs
26	VT	U	U	E	S	≤ 2yrs
27	LA	U	U	S	M	≤ 2yrs

Another consideration in proposing the nine candidate state-level HIE initiatives was whether they had received significant federal funding. Although an in-depth examination of the state-level HIE initiative's entire funding model is outside of scope of the current project, we were able to identify federal grant recipients. A mix of grantees from the following primary HIE granting entities are represented: ONC for the NHIN project, eHealth Initiative (eHI) funded by the Health Resource and Services Administration (HRSA), Agency for Healthcare Research and Quality (AHRQ), and then some state-level HIE initiatives that were not grant recipients from these federal sources. The nine candidate state-level HIE initiatives are distributed into these categories:

No Grant	AHRQ State or Regional Demonstration Contracts	ONC NHIN Contracts	eHI CCBH** Contracts
FL	CO	MA	CO
ME	IN	TN	IN
CA*	RI	IN	TN
	TN		MA
	UT		

*Note that some local HIE efforts in California were funded by eHI and NHIN, but the state-level HIE initiative entity (CalRHIO) has not received funding from these primary granting entities.

** Connecting Communities for Better Health program of the eHI.

4.1.3. Project Team

As mentioned, the phrase "Project Team" refers to the project staff, Steering Committee, and Technical Advisors who participated in this project. The Principal Investigator for this project was Victoria M. Prescott, Esq. Other project staff from AHIMA and the Foundation of Research and Education (FORE) assisted her in project planning, data collection, review of draft documents, conference preparation, and project management. Relevant biographical sketches are included in *Appendix B*.

The senior leaders of the nine state-level HIE initiatives were invited to serve on a Steering Committee for the project. During data collection, members of the Steering Committee provided information about their state-level HIE initiative and participated in on-site 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.

Technical Advisors were also engaged to provide specific advice in their particular area of expertise. Technical Advisors included experts from the legal, financial, economic, and technology sectors with experience in the formation and operation of HIE initiatives. Working with the Steering Committee and in support of the project staff, the Technical Advisors confirmed criteria for describing existing state-level initiatives, provided input into the information collection and interview process, reviewed the findings from data collection, and assisted in formulating guiding principles for developing state-level HIE initiatives.

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

NCSL participated fully in all the activities of the Technical Advisor role. In addition, NCSL contributed significantly to the project through input and guidance to the project staff at several staff meetings, by providing additional materials and resources on state government issues, and through helping the Project Team gain insight into how issues present themselves and are handled through state government systems. This input helped temper expectations of and further refine the possible role that state government can play in a state-level HIE initiative. NCSL also cosponsored, presented at, and helped secure involvement from stakeholders in state government for the public Consensus Conference. NCSL is also championing HIE efforts in the states through its Health Information Technology Champions initiative.²

4.1.4. Interview Templates—Process and Scope of Information to Be Gathered

The project staff conducted research including the before-mentioned literature review and conducted site visits to each selected state-level HIE initiative. To prepare adequately for the site visits, staff hosted a preliminary call with HIE initiative leaders. The two-day site visit discussions were guided by the points itemized in the information inventory matrix shown in *Appendix C*, which was developed by project staff and approved by ONC and the Technical Advisors. Information sought by project staff included information regarding market characteristics, formation, governance, initial funding, financial sustainability models, operations, HIE policies, short- and long-term priorities, and involvement with state and federal government. This information was summarized for each of the nine state-level HIE initiatives studied and a comparison chart of governing body structure was prepared, which both appear in the appendices to the *State-Level Health Information Exchange Initiative Development Workbook*, which is publicly available as a separate document with this Final Report.

4.1.5. Development of the Workbook

When the early results of the research revealed that there was no magic bullet model for a state-level HIE initiative, the Project Team discussed different options for the focus and format of the work product for this project. A workbook approach became the clear choice to provide a useful tool for other states seeking to form a state-level HIE initiative. As the Project Team concluded that consensus could not be reached on specific practices, they decided that a set of principles to guide the decisions involved in formation and start up of state-level efforts would be most useful. Specifically, guidance is detailed in the areas of governance, financing, operations, HIE policy development, and short- and long-term priorities. In addition, checklists and worksheets were prepared to assist in evaluating different options for one's state.

The *State-Level Health Information Exchange Initiative Development Workbook* is the compilation of knowledge resulting from field research, the expertise of the Project Team, and the input and suggestions from the attendees of the public Consensus Conference. The Workbook is designed for individuals interested or already involved in a state-level HIE initiative and policy makers who are considering how to guide their state in improving healthcare and lowering costs through HIE. These individuals could include those from state agencies; state legislatures; and providers, payers, or other stakeholders who have an interest in the statewide sharing of health information. The Workbook is intended to help focus, enhance, and organize the approach to developing a state-level HIE initiative. It reflects the consensus of the Project Team regarding development of a state-level

² <http://www.hitchampions.org/>

HIE initiative at this point in time. It serves as a baseline that may be enhanced as HIE organizations learn more about how to succeed in delivering real value for the citizens of their states.

Beginning with the vision and the need for state-level HIE initiatives, the *State-Level Health Information Exchange Initiative Development Workbook* is designed to correspond to a set of activities or processes to aid developing state-level HIE initiatives. Sections for each process include guiding principles (where applicable), worksheets and checklists for self-assessment, a discussion of pertinent issues, and examples of some states' practices (where useful). Results from the site visits to the nine states are included in the appendices to the Workbook. The examples used in the Workbook are not an endorsement per se but merely serve as an illustration of how a practice could be implemented.

Note that the scope of this *State-Level Health Information Exchange Initiative Development Workbook* is limited to the topics reviewed under the research project. It does not address every issue organizers will face. This Workbook should be used in conjunction with other resources and expert input. Any references and recommendations related to legal issues should not be construed as legal advice, and legal counsel should be consulted to ensure compliance with applicable laws and regulations.

4.2. Consensus Conference

4.2.1. Purpose and Goals

The public Consensus Conference was held July 18-19, 2006. The primary focus of the meeting was to provide a mid-project report to stakeholders, obtain feedback and input regarding the draft state-level HIE initiative's guiding principles and draft *State-Level Health Information Exchange Initiative Development Workbook*, and update attendees on the federal HIE efforts.

The Consensus Conference was designed to achieve maximum participation from attendees, which was emphasized in the opening remarks. A limited number of plenary sessions were included to update the audience on the project goals, methodology, and progress and to present a brief summary of a few state initiatives as background to discuss models and concepts. Comment and question periods were included during and at the end of each plenary session, and more extensive discussion with the attendees was facilitated through multiple breakout groups.

The public Consensus Conference was cosponsored by AHIMA's FORE and NCSL. The conference's agenda, as it appeared at the time, is attached as *Appendix D*³. A draft of the *State-Level Health Information Exchange Initiative Development Workbook* was released and publicized on the project's Web site one week before the Consensus Conference. A copy was also provided as part of the conference registration materials.

4.2.2. Attendees and Presenters

The public Consensus Conference was attended by more than 130 participants. Conference attendees included a cross section of those interested in the development of state-level HIE, including leadership from new and developing state-level HIE initiatives, private and public payers,

³ Note that subsequent to the public Consensus Conference, the Project Team decided that it would be more accurately descriptive to us the phrase "state-level HIE initiative," rather than "state-level RHIO."

federal and state government agency representatives, representatives from state legislative offices, providers, legal and business consultants, public and private health policy collaboratives, and HIT vendors. The agenda for the Consensus Conference, including the list of presenters, is included as *Appendix D*.

4.2.3. Outcomes

Attendees gave the Project Team positive feedback during the public Consensus Conference about the usefulness of the *State-Level Health Information Exchange Initiative Development Workbook*, in that it helped them think through the issues that affect the HIE development in their states and formulate feasible approaches. During the breakout sessions on the various topics, the attendees gave valuable input on the various guiding principles and suggested some new ideas for inclusion in the *State-Level Health Information Exchange Initiative Development Workbook*, which were then incorporated.

Many attendees also made suggestions regarding the creation of a sustainable community of state-level HIE initiatives to continue the conversations regarding the key issues that are faced and sharing of ways to overcome them, as well as continued additions to the *State-Level Health Information Exchange Initiative Development Workbook* as new ideas and approaches are developed.

As part of the post-conference feedback, attendees completed an evaluation, which specifically asked them to rate the value of the *State-Level Health Information Exchange Initiative Development Workbook*, with 71 percent of respondents rating it as outstanding and 25 percent rating it as good (on a scale of outstanding, good, fair, poor). The ratings for the Consensus Conference were also positive, with 44 percent of respondents ranking the conference presentations and breakout sessions as outstanding and 51 percent ranking them as good.

5. Key Findings

On the basis of the data from the nine state-level HIE initiatives and confirmed through discussions at the Consensus Conference, this study revealed that:

- (1) Most state-level HIE initiatives are still in an early stage of development;
- (2) They differ in their origins, drivers, and goals;
- (3) They reflect the uniqueness of their market characteristics;
- (4) They used a wide variety of approaches; and
- (5) They are all rapidly evolving organizations committed to improving healthcare in their states.

The *State-Level Health Information Exchange Initiative Development Workbook* available as a separate document with this Final Report, is the key deliverable of this research. It reveals all that was learned from data collection and the analysis of survey findings about the vision, processes, and guidance to develop sustainable state-level HIE initiatives to advance healthcare. Key findings are highlighted in this section, but the reader should reference the *State-Level Health Information Exchange Initiative Development Workbook* for the detail.

5.1. Vision and Need for State-Level HIE Initiatives

Significant improvement in the quality and safety of healthcare, increased efficiency and reduction in costs, facilitation of research, and enhancement of public health are the key goals of sharing electronic health information securely among stakeholders while protecting patient privacy. Although much attention has been focused on local HIE efforts across the country, more recently, the importance of a statewide view has been recognized.

A state-level HIE initiative is in a special position, through its public-private approach, to carry out functions best done by a single entity at the state level, such as convening stakeholders across the state, state government, and local HIE efforts to foster collaboration and coordination. State-level HIE initiatives can play an integral role in balancing the rights and needs of all residents (including the underserved), while facilitating the removal or mitigation of statewide barriers to HIE through state-level policy changes. The state-level HIE initiative can also serve as a conduit for consensus on and adoption of standards and as a bridge for coordination with other states and the nationwide health information network efforts.

5.2. Development Process

Key activities for developing state-level HIE initiatives were identified and described. These activities characterize the essential steps in forming any organization. In this context, they are more complex because of the need to convene and secure support from multiple stakeholders that have not typically worked together to advance the state's healthcare system. They are as follows:

1. Assess Market Characteristics
2. Identify Champions and Key Stakeholders
3. Determine the Role of the State-Level HIE Initiative
4. Establish Governance Structure

5. Obtain Initial Funding
6. Concurrently Develop Financial Model for Sustainability, Formulate HIE Policies, and Set Up Operations and (if applicable) Technology
7. Identify Short- and Long-Term Priorities
8. Reassess Original Assumptions and Plans Often, Expect Change, and Adjust Accordingly

These activities often occur in parallel rather than sequentially. For example, one could receive initial funding before determining the role of the state-level HIE initiative, or one could be setting up operations while still establishing a governance structure. Note that activity 6 actually is a combination of three activities that are interdependent and should be considered in tandem.

Balancing resource use among these activities can also be challenging. One activity should not consume significant resources at the expense of the other activities. Activity 7, identifying short- and long-term priorities, often comes as a result of activities 1 through 6.

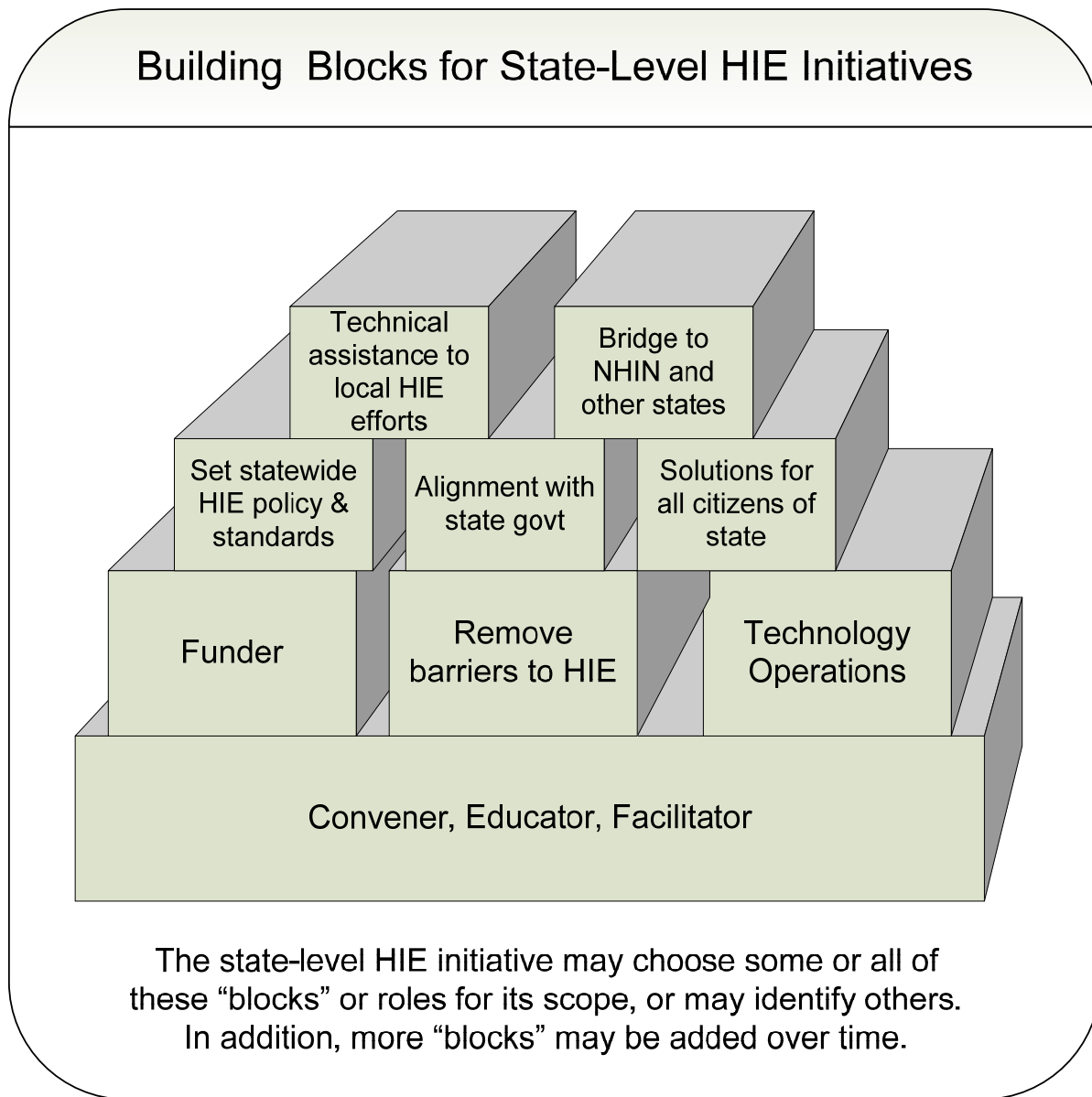
A state-level HIE initiative does not have to tackle all activities at once, and there does not have to be consensus among all the stakeholders to move forward. Depending on how much HIE activity is already under way and the history of collaboration among stakeholders in the state, the organizational development process can be slow or fast. Throughout this development process, the vision of the benefits of sharing health information must be kept at the forefront.

5.3. Role of State-Level HIE Initiatives

The role of the state-level HIE initiative should be determined early on the basis of the state's needs and priorities. The role of state government must also be explored. Careful business planning is essential to creating a sustainable venture and research on what services or products are feasible and what resources can be used is a prerequisite to formulating a viable course of action.

5.3.1. Functions

Many factors can influence the role the state-level HIE initiative will serve for a state. However, a number of different functions or roles that a state-level HIE initiative could choose to assume were identified, which are graphically depicted as "building blocks" in *Figure 2*.

Figure 2.

5.3.2. Role of State Government

State government is a stakeholder in healthcare in important ways: as payer, employer, provider, public health, policy maker, regulator, and licensing entity for healthcare providers. A state can leverage its marketing power as a large payer to foster a uniform approach to negotiating with national organizations in conjunction with or on behalf of communities within the state.

States’ responsibility for healthcare goes beyond financing individual care. States have an imperative to ensure availability and quality of healthcare for a number of different groups (e.g., Medicaid recipients, persons with disabilities, the elderly, children, the underserved, public health). As is the case with public infrastructure, law enforcement, education, and a broad range of other social goods, states invest in the long-term health of all their citizens. Governments typically

support infrastructures and fund research and development as public goods. States are arguably in a unique position to improve healthcare as their citizens migrate among delivery sites and payment structures.

States regulate the healthcare sector in a number of ways: through broad policy setting, licensure, implementation and enforcement of regulations, and incentives tied to financing. These roles offer a number of opportunities for promoting public objectives related to HIE statewide and removing barriers to HIE.

The state's public health function and its relationship to county and local health departments put it in a unique position to spur appropriate HIE among providers and public health departments for the purposes of biosurveillance and detection of bioterrorism, disease outbreaks, and pandemics so that early response can be initiated. Public health departments often are already collecting some data (such as immunizations), so they could also be a valuable source of data for HIE purposes.

Last, but not least, states are in an exclusive position in the intergovernmental system between the federal government and local communities. They have a special role in representing all their residents in interactions across their communities, with their neighboring states, and with the federal government.

5.4. Governance

The state-level HIE initiative does not need a formal governance structure before beginning valuable work in support of the vision of sharing healthcare data. Many activities, such as pilot projects, can be undertaken without a formal governance structure. However, it is advisable to begin formulating what type of decision-making structure is appropriate for the long-term sustainability of the state-level HIE initiative.

Several aspects need to be considered: (a) source of authority or power, (b) choice of legal entity or decision not to form a legal entity, (c) governing structure (e.g., Board of Directors, management committee), and (d) approach to transparency. A short comparison of the nine states studied in this project is included in the last appendix of the *State-Level Health Information Exchange Initiative Development Workbook*.

5.5. Initial Funding and Financial Sustainability

5.5.1. Initial Funding

A state-level HIE initiative has a number of funding sources, which could include the state itself. The sources for funding may be affected by the type of legal entity (e.g., nonprofit corporations can receive grants, in most cases). Potential sources of initial funding should be evaluated by assessing the effort required (risk) and the potential funding amount (reward), while balancing the requirements of the contract or grant with the long-term vision of statewide HIE to improve healthcare and reduce costs. The most important purposes of initial funding are to:

- (1) Build a strong consensus among multiple stakeholders with respect to the purpose and functions of the state-level HIE initiative;

- (2) Define the role of state government in assisting the state-level HIE initiative;
- (3) Put in place a decision-making structure; and
- (4) Develop a detailed, comprehensive business plan for the state-level HIE initiative, which includes defining capital and operating expenses and the sources of revenue.

Initial funding can also be used for other aspects, such as building the technology infrastructure, if the state-level HIE initiative will be conducting such work; however, this funding should be balanced with the need to ensure a viable structure and plan for the state-level HIE initiative at the outset.

5.5.2. Financial Sustainability

There is no magic bullet today with respect to the options or strategies to achieve long-term financial sustainability. Many state-level HIE initiatives are still struggling to get started and conduct HIE, whereas the more mature initiatives are faced with challenges on how to expand their services in a financially sustainable way. Financial sustainability is a critical issue for all HIE initiatives, even those that are relatively more mature. The financial model can be expected to evolve over time as market characteristics continue to change.

The building blocks chosen for the state-level HIE initiative will determine the range of options for financial models and sustainability long term. Some building blocks may be able to generate revenue, but others may not. For state-level HIE initiatives with technology operations, it may be helpful to frame the funding steps around phases, such as:

- a) infrastructure development (e.g., staff, resources, hardware, operating system, database software),
- b) capacity building to enable the receiving and sharing of healthcare data (e.g., building master patient index, clinician index, interfaces to data source systems), and
- c) quality improvement after enough data are available (e.g., research, aggregate reporting).

The level and type of financing that state government is willing or able to provide a state-level HIE initiative will have a significant effect on the long-term financing. The state-level HIE initiative needs to determine how its own initiatives will dovetail with the state's agenda and how funding made available through the state will support those activities.

Some potential revenue models for the state-level HIE initiative were outlined:

- **Membership Fee Model**—Stakeholders pay to support shared services for all. Membership fees could be equal for all participants or tiered on the basis of some factor, such as size or use. This Membership Fee Model requires careful consideration of how to set up the participation on the basis of the relative value each participant expects to receive from the shared enterprise. In addition, getting a commitment from a critical mass of members is essential to the financial success of this model.

- **HIE Transaction Fee Model**—The state-level HIE initiative charges transaction fees for its HIE services or products on the basis of benefit to the participants. Examples include:
 - Transactional fee of \$X per clinical result delivered
 - Transactional fee of \$X per covered life per month
 - \$X per hour for technical assistance
 - \$X per month for a license to use a particular software package on the WebUnlike the Membership Fee Model, in which participants sign on up front to participate, the HIE Transaction Fee Model requires investment capital or grants to build an infrastructure for the business.
- **Program and Service Fee Model**—This model involves charging stakeholders for participation in, or outcomes from participation in, program-related activities undertaken by the state-level HIE initiative. For example, fees could be charged for creation and implementation of group purchasing arrangements.
- **Combination of Models**—One single model may not cover long-term expenses; therefore, it may be beneficial to use a combination of financial models, where it makes sense. Many combinations of the models described may be viable for a state-level HIE initiative. For example, a Membership Fee Model could supply some small core funding on a steady basis, and the HIE Transaction Fee Model could be used to supplement at the same time. Some models may not yet be feasible for the state-level HIE initiative, depending on its stage of development. For example, a state-level HIE initiative just forming may not have services capable of generating HIE transaction fees sufficient to cover its costs.

5.6. *HIE Policies*

A state-level HIE initiative's policy framework within which HIE participants will operate is important to consider (e.g., are there core principles that the stakeholders agree that all data sharing shall be based on?). HIE policy development should not occur in a vacuum but rather be coordinated with the persons involved in, and assessed in light of, the development of the financial model. The complexity, cost, and usability of the technology solutions and required ongoing support must be considered. Also, the advice of legal counsel is necessary to understand the risk and liability of policy decisions and to establish the infrastructure necessary to ensure compliance with policies established, contract terms, and state and federal law. Effects of HIE policy decisions should be carefully weighed with these other factors to ensure a feasible policy framework is achieved that will result in a sustainable statewide HIE initiative that improves care and reduces cost.

Data-sharing agreements often reflect the understanding among the parties providing and receiving the healthcare data and detail the constraints regarding authorized use and disclosure of healthcare information. Some key topics to address in a data-sharing arrangement are described.

During the data collection and site visits, some preliminary findings on barriers to statewide HIE were documented. Specific barriers to HIE in a state will be determined by business practice and state law. Many states have enacted laws that affect HIE. States must vigilantly pursue investigating these issues with legal counsel to ensure that their plans comply with the law. Solutions to some

barriers could be developed through state-level policy changes or legislation, and the state-level HIE initiative should consider its options to facilitate such change to advance HIE. Some of the barriers may be a result of a misunderstanding or lack of knowledge about state law or policy, and the state-level HIE initiative can use its educational role and/or issue policy statements to bring everyone to a common level of understanding.

Although opinions on HIE policies with respect to patient consent were outside the scope of this project, several general principles were outlined to guide the state-level HIE initiative in formulating its policies that comply with state law and stakeholders' consensus. It is also imperative that the state-level HIE initiative understand the realities of designing, implementing, and administering the particular HIE policies and their anticipated effect on the state-level HIE initiative's potential liability. The interdependence of the decisions on HIE policies, financial sustainability, and operations is key to shaping short- and long-term priorities, successful planning, and achieving long-term viability.

6. Dissemination Plan

6.1 Key Audiences

The Project Team identified key audiences who would benefit from this Final Report and the *State-Level Health Information Exchange Initiative Development Workbook*, and who could be influential in encouraging application of the principles and findings to further development of state-level HIE initiatives. The broad target audiences are:

- State Government, and specifically state legislatures and governors
- Federal Government, including Congress and federal offices and agencies
- Public Health Agencies
- Providers
- Payers
- Regional HIEs
- National associations with constituents who are interested in or influential in this area
- IT vendors and consultants
- Consumer groups

A list of organizations and channels identified for reaching these audiences is detailed in Appendix E. We have identified vehicles for reaching these audiences and suggest a combination of press releases, Web distribution, utilization of Steering Committee members as a speaker's bureau, and other mechanisms to disseminate the Final Report findings and Workbook resources. The following are the key findings from this research that can be used to create focused talking points for release of the Workbook and Report

7. Conclusions and Recommendations

This 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. Leaders from the nine HIE initiatives, along with other subject-matter experts, convened to reach consensus on a series of practical steps to cultivate and build sustainable statewide HIEs in concert with nationwide efforts.

Because of the nascence of state-level HIE initiatives and differences in market characteristics among states, there is no single recommended model (one-size-fits all approach); however, the Project Team compiled a set of guiding principles and planning worksheets and checklists that are presented in the *State-Level Health Information Exchange Initiative Development Workbook*, which is publicly available in a separate document with this Final Report. These represent the Team's best advice at this point in time for developing organizations.

This project helped clarify the importance of state-level HIE initiatives and the roles that can only be assumed by a state-level entity. State-level HIEs can be the bridge between communities, neighboring states, and nationwide initiatives. They can set HIE policy and standards and ensure alignment of laws and regulations. They can provide HIE services, or they can provide technical assistance and support to local entities who provide these services. They can also help catalyze

health information improvements in state governmental agencies, a need that has not been widely acknowledged. State government is a stakeholder as a payer, employer, provider, regulator, and public health authority.

Analysis of findings revealed a number of barriers shared by even the most experienced state-level HIEs. Some barriers reflect the pioneering nature of this work and the challenge of building a sustainable multi-stakeholder organization. Others involve the place of the state-level HIE in nationwide health information network activities. Major barriers include:

- Securing funding for start up, organization building and to sustain organizations over time
- Lack of consensus on the most effective role for state government in HIE and the lack of coordination among state agencies
- Minimal participation and support from private payers
- Non-aligned stakeholder interests
- Lack of shared experience with start up projects that produce results
- No roadmap for how state-level HIE relates to federal NHIN programs or how contiguous states should relate to one another regarding HIE.
- Informal or insufficient mechanisms for knowledge sharing among state-level organizations

Despite the need for collaborative work to address each of these barriers, the Project Team advises against any form of mandate on state-level HIEs or any action that would lock in one particular approach. A clear federal position in support of effective state-level HIE initiatives in each state would accelerate progress. This is a time for innovation and learning, but more effective channels for sharing lessons learned are needed.

In addition to the Workbook, the Project Team formulated the following recommendations for further research and development. They are prioritized in order of urgency.

Recommendations	
1	<p>Institute mechanisms to promote strategic synergy between state and federal health information exchange (HIE) agendas and initiatives:</p> <ol style="list-style-type: none"> 1. Establish a coordinating body to promote communication and collaboration among states and between states and federal agencies to advance HIE. This coordinating body will address areas of concern and opportunities for effective action through collaboration. It will ensure clear communications with and among states and a voice for state issues in the federal agenda. 2. Consider how the American Health Information Community and Office of the National Coordinator can work with state and national policy makers to address the barriers state-level HIE initiatives encounter. 3. Develop mechanisms to engage state-level HIE initiatives in the development and deployment of relevant federal initiatives, including feedback on the effect of the federal HIT and HIE agenda.

2	<p>Identify salient financial models for sustainable HIE that state-level HIE initiatives can apply:</p> <ol style="list-style-type: none"> 1. Inventory and describe in detail HIE projects that have achieved financial sustainability and are demonstrating positive outcomes or appear to have identified sufficient revenues and cost data to argue for financial sustainability. 2. Identify revenue models currently in use that have generated real savings or revenue and improvement. 3. Analyze the programmatic details of each model. <ol style="list-style-type: none"> a. Describe pros and cons for each: ease of implementation, the infrastructure needed, requisite state-level policy features, the critical mass of stakeholders that need to be involved, the market characteristics that make the model feasible, how healthcare is affected or improved, the estimated costs and revenue from the model, and the expected timing for design and implementation. b. Recommend implementation approaches. 4. Identify the top few most feasible options for early successful HIE implementation. 5. Identify models the complexity and cost of which suggest that they be deferred. 6. Recommend how to disseminate these results.
3	<p>Conduct an analysis in the areas listed below to understand and leverage the role and influence of public and private payers in advancing HIE initiatives, and develop and implement a payer involvement strategy for HIE.</p> <ol style="list-style-type: none"> 1. Roles payers (public and private) have in statewide and local HIE initiatives: <ol style="list-style-type: none"> a. The criticality of involving payers (public or private), b. When engagement is most beneficial, c. How to engage payers, and d. The feasibility of a national strategy to create common methodologies for payer contribution to HIT financing. 2. The importance of state Medicaid and Medicare programs' participation in state-level HIE initiatives: <ol style="list-style-type: none"> a. Ways in which Centers for Medicare & Medicaid Services (CMS) policy might accelerate or constrain the ability of state Medicaid to take actions to facilitate HIE. b. Identify how to engage CMS and other public payers early in the design process to ensure aligned agendas. c. How adoption of Medicaid Information Technology Architecture (MITA) affects HIE. d. Identify how to ensure integration of Medicare and Medicaid population data for HIE purposes. e. Make recommendations for any federal statutory changes that may be necessary to integrate Medicaid and Medicare in this way. 3. The private payer perspective (including traditional health plans and self-funded plans): <ol style="list-style-type: none"> a. Business goals, strategic direction, collaborative and competitive advantage as it relates to multi-stakeholder HIE. b. Specifically consider how the evolution of payer-sponsored personal health records (PHRs) may affect HIE initiatives. 4. Identify ways for payers to collaborate and support HIE. 5. Identify and describe risks that payers may inhibit HIE or block innovation.

	<ol style="list-style-type: none"> 6. Identify and consider any limitations or downsides of market-driven evolution of HIE with respect to payers. 7. How public payers influence and affect private payer behavior. 8. How states' payer mix affects HIE (e.g., number of payers, types of payers, respective market share). 9. The effect of federal regulation of employer benefits (e.g., Employee Retirement Income Security Act (ERISA), Health Insurance Portability and Accountability Act of 1996 (HIPAA) and other regulations on state-level HIE. 10. The role of public employee and retiree coverage and care (e.g., U.S. Department of Veterans Affairs, U.S. Department of Defense, federal employee program, state employee program) in HIE.
4	<p>Advance understanding of how state policy makers and government can best be involved in state-level HIE initiatives:</p> <ol style="list-style-type: none"> 1. Identify the most feasible and productive ways for state governments and policy makers to provide leadership for HIE. <ol style="list-style-type: none"> a. Should the state designate the state-level HIE initiative? b. If so, how is this best accomplished (e.g., governor, Department of Health, Medicaid, state legislature, state licensure division, by means of consensus, bidding, appointment)? c. State government should communicate internally and coordinate between the various state agencies and departments to develop and implement a unified approach for the state HIE agenda and collaborate on ways to reduce internal barriers to statewide HIE. 2. Develop models of how state government can collaborate with the private sector to develop public-private vehicle to advance HIE, including: <ol style="list-style-type: none"> a. How to engage state government while remaining flexible to respond to market demands for healthcare (e.g., healthcare costs, availability, quality, effect on business climate). b. Role of state government in the relationship (e.g., more as a regulator or more as a partner similar to economic development function). Consider the minimal role that state government can play in creating an environment for engaging portions of the private sector that can respond to market demand issues. c. Options for formal entities or vehicles that involve public and private sectors in HIE, including pros and cons of each. d. How to take advantage of opportunities available only to a state-level public-private HIE initiative. e. Examine what has worked in other industries. f. How to maintain the necessary balance required to grow the public-private partnership. g. Consider developing standard language that federal, state, and other purchasers of healthcare can include in their contracting cycle to facilitate the deployment of HIT and ensure interoperability while not negatively affecting the business climate unnecessarily. 3. Engage with NCSL, National Governors' Association (NGA), and other key stakeholder groups to discuss these issues.

5	<p>Develop ways to support state-level HIE initiatives, including:</p> <ol style="list-style-type: none">1. Develop a plan for creating a “learning community” of state-level HIE initiatives:<ol style="list-style-type: none">a. Accelerate information sharing through education and communication mechanisms, such as webinars, discussion forums, listserv, periodic meetings (e.g., regional, national, quarterly, annually).b. Continue to refine the <i>State-Level Health Information Exchange Initiative Development Workbook</i> developed through this project and/or create supplementary tools based on it. Examples of such tools include PowerPoint presentations, consumer-education booklets, and other materials deemed valuable by the state.c. Explore development of a Web site as a resource.d. Consider developing content to educate all stakeholders on the benefits of HIE, framing it as a global healthcare and economic issue rather than simply a technology initiative.2. Determine the ways to reach out to and engage states in the learning community through coordinated efforts of various entities (e.g., through NGA, NCSL).3. Support for HIE Executive Directors from initial formative stages through more advanced operations of the state-level HIE initiative through consulting, mentoring, and formal training resources.
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It is clear that the work of state-level HIE initiatives has only just begun. Fostering close communication and collaboration within a state, among states, and with the federal government to coordinate efforts and share successes and challenges with each other will accelerate realizing the ultimate goal of improved healthcare and reduced cost through secure, interoperable, nationwide HIE.

Appendix A - Bibliography

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Appendix B - Project Staff Biographical Sketches

Victoria M. Prescott, Esq.

Ms. Prescott served as the Principal Investigator on this project as an independent consultant for AHIMA FORE. Ms. Prescott is currently serving as General Counsel and Business Development Specialist for Regenstrief Institute, an international leader in medical informatics research and HIE. Since joining Regenstrief in 2003, she has served as project manager for Indiana Medicaid chronic disease management program; co-leader of clinical messaging project; and co-leader of medication history project. She has assisted on a biosurveillance project for the Indiana State Department of Health (ISDH); assisted in the formation and development of the Indiana Health Information Exchange, Inc.; assisted in the e-prescribing project; currently leads the Health Information Security and Privacy Collaborative (HISPC) subcontract from ISDH; and assists in the clinical quality project that plans to use clinical and administrative data to support pay-for-performance initiatives. She deals daily with legal issues of HIE, the negotiation of related contracts, and compliance with HIPAA and other laws. Ms. Prescott served as subcommittee co-chair in the Markle Foundation's Connection for Health project and also as primary author on portions of the Common Framework released earlier this year.

Ms. Prescott has more than 15 years of experience as an attorney, with an emphasis on intellectual property licensing, contract negotiation, and health law. She served as in-house counsel for public and private companies, such as Mattel Toys and Resort Condominiums International. Ms. Prescott also has a broad business background, including development and implementation of business models, business process engineering, operations, software design and programming, data models and architecture, and health data standards. More recently, she founded and built Licensoft, Inc., a company specializing in the development, marketing, and support of intellectual property license tracking software. She later sold the company to a New York Internet corporation and remained on as division head for a year, after which she did legal and business consulting for two years before joining Regenstrief, focusing her efforts in the life science and technology industries.

Ms. Prescott is a frequent speaker and author on topics related to HIE, policy development, entrepreneurship, and business development. She holds a law degree from Southern Methodist University School of Law and a Bachelor of Science degree from Indiana University School of Business. She is admitted to practice law in California and Indiana.

KaLea A. Lehman

Mrs. Lehman served as an independent consultant and research assistant to AHIMA FORE on this project. Mrs. Lehman also studies sociology at the George Washington University.

Mrs. Lehman served as a Policy Analyst for the Commission on Systemic Interoperability (CSI) in 2005 where she analyzed the relation and need for connected and interoperable healthcare in rural areas, special populations, and the areas of public health and homeland security. While working with CSI, Mrs. Lehman also managed outreach campaigns to Congress and the general public along with the CSI's public relations firm. Before her work with CSI, she worked in the Office of Communications and Public Liaison at the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) at the National Institutes of Health (NIH). Mrs. Lehman has been involved in advocacy and public speaking efforts for rheumatic disease and served on the National Advisory Board for the Scleroderma Foundation in 2005.

Appendix C - Interview Inventory Matrix

Appendix D - Public Consensus Conference Agenda



**Consensus Conference:
Development of State Level RHIOs**
Sheraton National Hotel – Arlington, VA
July 18-19, 2006

Conference Goals

- Provide a mid project report to stakeholders on the research into practices at State Level RHIOs, a project funded by the Office of the National Coordinator
- Discuss concepts, models and definitions regarding State Level RHIO
- Describe governance, funding, and health information exchange principles and sample practices
- Solicit feedback to formulate guidance materials for developing State Level RHIOs
- Envision opportunities for State Level RHIOs to advance nation-wide initiatives to improve health care through information exchange

Tuesday, July 18, 2006

8:30 am – 5:00 pm Registration – North and South Lobby

General Sessions – North Ballroom

- 10:00 am Welcome and Project Overview
Molly Coye, MD, MPH - Chair, Project Steering Committee
Linda Kloss, RHIA, CAE - CEO, AHIMA and FORE
- 10:30 am Project Goals and Vision of the Office of the National Coordinator
Kelly Cronin - Director, Office of Programs and Coordination
- 10:45 am Project Methodology and Conference Overview
Viki Prescott, Esq. - Principal Investigator
- 11:00 am State-Level RHIO Concepts, Models and Definitions
Molly Coye, MD, MPH (Facilitator) – CEO, Health Technology Center
Kala Ladenheim – Program Director, Forum for State Health Policy Leadership, National Council of State Legislatures
Lisa Rawlins – Bureau Chief, Florida Center for Health Information and Policy, Florida Health Information Network
Laura Adams – CEO, Rhode Island Quality Institute
Antoine Agassi – Director & Chair, State of Tennessee eHealth Council
Shaun Grannis, MD –Investigator, Regenstrief Institute for Health Care
- 12:30 pm Lunch - South Ballroom

Workgroup Breakouts

- 1:30 pm Principles and Practices Workgroup: Discussion of Findings in Facilitated Workgroups
 1. Governance – Cavalier Room
 2. Funding & Financial Sustainability – Concourse #1
 3. Health Information Exchange Policies – Concourse #2
- 3:00 pm Break – Foyer
- 3:30 pm Principles and Practices Workgroup: Discussion of Findings in Facilitated Workgroups
 1. Governance – Cavalier Room
 2. Funding & Financial Sustainability – Concourse #1
 3. Health Information Exchange Policies – Concourse #2
- 5:00 pm Networking Reception – Foyer

Sponsored by a grant to FORE from 

Wednesday, July 19, 2006

- 8:00 am Registration – North and South Lobby
- 8:30 am Continental Breakfast – South Ballroom

Sponsored by a grant to FORE from 

General Sessions – North Ballroom

- 9:00 am Summary Reports from Workgroups
- 10:15 am Break – Assembly Foyer
- 10:30 am State-Level RHIOs and the Nationwide Health IT Agenda
John Loonsk, MD - Director, Office of Interoperability and Standards, ONC
Kelly Cronin - Director, Office of Programs and Coordination, ONC
P. Jon White, MD – Health IT Portfolio Manager, AHRQ
Kala Ladenheim – Program Director, Forum for State Health Policy Leadership, National Council of State Legislatures
- 11:30 am What We Learned at this Conference
 Dissemination and Use of Project Findings
Molly Coye, MD, MPH - Chair, Project Steering Committee
- 12:00 pm Adjourn

Appendix E - Dissemination Channels And Talking Points

Target Audience	Channels	
State government: specifically State legislatures and governors	National Conference of State Legislatures www.ncsl.org	Publication: <i>State Health Notes</i> Conference: August 15 – 16, 2006
	National Governors Association www.nga.org	Publication: newsletters Conference: Aug 5 – 7, 2006
	American Public Human Services Association www.aphsa.org	Publications: <i>Policy and Practice Magazine, This Week in Washington, This Week in Health, The Medicaid Management Institute Bulletin</i> Conference: July 9- 11, 2006
	National Association of Insurance Commissioners www.naic.org	Publications: https://external-apps.naic.org/incPubs/index.jsp Conferences: December 9-12, 2006; March 10 – 13, 2007; June 2 – 5, 2007; Sept 29-Oct 2, 2007
	National Association of Attorneys General www.naag.org	Publications: none listed Conference: June 27-30, 2006
	National Association of Counties www.naco.org	Publications: letters, briefs, short publications on Web site Conference: August 4-8, 2006
	National Association of State Mental Health Program Directors www.nasmhpd.org	Publications: reports and one-time publications on Web site Conference: not listed
	National Association for State Comprehensive Health Plans www.naschip.org	Publications: Reports Conference: Oct 18-20, 2006
	National Association of State Medicaid Directors www.nasmd.org	Publications: <i>Medicaid Management Institute Bulletin</i> Conference: Fall Meeting November 13-15, 2006; Spring Meeting June
	Council of State Government www.statesnews.org	Publications: State News Magazine Conference: Nov 30- Dec 3, 2006
	American Health Information Management Association/Component State Associations www.ahima.org	
	National Association of State Budget Officers www.nasbo.org	Publications: <i>Washington Report, informational briefs, research reports</i> Conference: July 29-August 1, 2007; Spring meeting April 20-21, 2007, Fall meeting October 20-22, 2006
	National Rural Health Association www.nrharural.org	Publications: <i>Journal of Rural Health, Rural Clinician Quarterly, NRHA e-News</i> Conference: May 14-18, 2007

Target Audience	Channels	
Federal Government and Agencies	Health Resource and Services Administration www.hrsa.gov	
	Center for Medicare and Medicaid Services www.cms.hhs.gov	
	Indian Health Service www.ihs.gov	
	Centers for Disease Control and Prevention www.cdc.gov	
	Agency for Health Research and Quality www.ahrq.org	AHRQ National Resource Center for Health Information Technology
	National Institute of Standards and Technology www.nist.gov	
	Department of Labor www.dol.gov	
	Department of Treasury www.treasury.gov	
	Department of Commerce www.doc.gov	
	Department of Defense www.dod.gov	
	Department of Veteran's Affairs www.va.gov	
	Department of Homeland Security www.dhs.gov	
	Congress	Steering Committee on Telehealth and Healthcare Informatics
Congressional staff		Monthly education sessions
Other key committees		testimony
Public health agencies	Association of State and Territorial Health Organizations www.astho.org	Publications: <i>Environmental Health News</i> , <i>Public Health Preparedness</i> , <i>Primary Care and Prevention Network News</i> , <i>E-Health</i> , <i>Immunization News</i> , <i>Health and Environment Electronic</i> , <i>Adolescent and School Health Update</i> , <i>ASTHO Report</i> (some may be 1 time reports) Conference: Sept 12-15, 2006
	American Public Health Association www.apha.org	Publications: <i>American Journal of Public Health</i> , <i>The Nation's Health</i> Conference: November 4-8, 2006
	American Health Planning Association www.ahpanet.org	Publications: <i>Health Planning Today</i>
	National Association of Health Data Organizations www.nahdo.org	Publications: <i>NAHDO News</i> , various reports Conference: December 4-5, 2006
	Public Health Data Standards Consortium www.cdc.gov/nchs.othreact/phdsc	
	National Association of County and City Health Officials www.naccho.org	Conference: February 19-23, 2007

Target Audience	Channels	
Providers	American Academy of Family Physicians www.aafp.org	Publications: <i>American Family Physician, Family Practice Management, Annals of Family Medicine</i> Conference: Sept. 27 – October 1, 2006
	National Association for Home Care and Hospice www.nahc.org	Publications: <i>Caring Magazine, Home Care and Hospice News</i> Conferences: October 15-18, 2006
	American Association of Homes and Services for the Aging www.aahsa.org	Publications: <i>Weekly Perspectives, FutureAge</i> Conferences: Nov. 5-8, 2006; Future of Aging, March 19-21, 2007
	American Clinical Laboratory Association www.clinical-labs.org	Publications: <i>Results newsletter</i> , Conferences:
	American College of Physicians www.acponline.org	Publications: <i>Annals of Internal Medicine, ObserverWeekly, ACP Observer</i> Conferences: April 19-21, 2007
	American Health Care Association www.ahca.org	Publications: <i>Provider</i> Conferences: October 8-11, 2006
	American Hospital Association www.aha.org	Publications: <i>AHA NewsNow, AHA News</i> Conferences: May 6-9, 2007
	American Medical Association www.ama-assn.org	Publications: <i>American Medical News, JAMA</i> Conferences: August 2007
	American Medical Group Association www.amga.org	Publications: <i>Group Practice Journal, Inside AMGA, E-News</i> Conferences: February 28 – March 3, 2007
	American Nursing Association www.nursingworld.org	Publications: <i>American Nurse Today, The American Nurse, American Journal of Nursing, online Journal of Issues in Nursing</i> Conferences:
	American Pharmacists Association www.aphanet.org	Publications: <i>Pharmacy Today, Journal of the American Pharmacists Association</i> Conferences: March 16-19, 2007
	American Psychiatric Association www.psych.org	Publications: <i>American Journal of Psychiatry, Psychiatric News</i> Conferences: May 19-24, 2007
	Federation of American Hospitals www.fah.org	Publications: <i>Hospital Outlook</i> Conferences: March 4-7, 2007
	Medical Group Management Association www.mgma.org	Publications: <i>MGMA Connexion, ACMPE Executive View</i> Conferences: October 22-25, 2006
	National Association of Chain Drug Stores www.nacds.org	Publications: <i>The Practice Memo, CEO/Issue Update</i> Conferences: April 21-25, 2007
	National Association of Children's Hospitals and Related Institutions www.nachri.org	Publications: <i>Children's Hospitals Today, specialty bulletins, Washington Update</i> Conferences: October 8-11, 2006
	National Association of Community Health Centers www.nachc.org	Publications: <i>Community Health Forum Magazine</i> Conferences: August 24-28, 2007
National Community Pharmacists Association www.ncpanet.org	Publications: <i>America's Pharmacist, e-News, NCPA Newsletter</i> Conferences: October 7-11, 2006; Legislative Affairs May 13-16, 2007	
State Hospital Associations	Via A ² HA	

Target Audience	Channels	
Payers	America's Health Insurance Plans www.ahip.org	Publications: Conferences: State Issues Conference, Oct. 31 – Nov. 2, 2006; Executive Leadership Summit, Medicare and Medicaid Conference, National Policy Forum
	Blue Cross and Blue Shield of America www.bluecares.org	Publications: Conferences:
	National Business Coalition on Health www.nbch.org	Conferences: November 5-7, 2006
	Small Business Health Plans www.ahdpsnow.com	Publications: Conferences:
	US Chamber of Commerce www.uschamber.com	Publications: Conferences:
	Washington Business Group on Health www.wbgh.org	Publications: <i>Washington Business Health Updates, Policy Alerts, Issue Briefs</i> Conferences: November 28-20, 2006
National Groups	American Medical Informatics Association www.amia.org	Publications: <i>Journal of the American Medical Informatics Associations</i> , policy papers Conference: Nov 11-15, 2006
	Health Information and Management Systems Society www.himss.org	Publications: <i>Journal of Health Information Management, HIMSS Enews, HIMSS Insider</i> Conference: Feb 25- March 1, 2007
	American Medical Association www.ama-assn.org	Publications: <i>Journal of the American Medical Association, AMA Voice, American Medical News</i> Conference: June 10-14, 2006
	EHI Connecting Communities for Better Health http://www.ehealthinitiative.org/	Publications: <i>eHI Smart Brief</i> Meetings: Sept 13-14, 2006; September 25-27, 2006
	Nationwide Health Information Network http://nhinwatch.com	Publications: Web site news Meetings: various events listed at http://nhinwatch.com/page.cms?pageld=6
	American Health Lawyers Association www.healthlawyers.org	Publications: <i>Health Lawyers Weekly, Journal of Health Law</i> Conferences: June 25-27, 2007, numerous special topic conferences
	American Bar Association/Health Law Section www.abanet.org/health/	Publications: <i>The Health Lawyer, ABA Health eSource</i> Conferences: October 23-24, 2006,
	Healthcare Leadership Council www.hlc.org	
	National Alliance for Health Information Technology www.nahit.org	
Foundations	Markle Foundation www.markle.org	
	Robert Wood Johnson Foundation www.rwjf.org	Publications: <i>ABA Bankers News, ABA eAlert, ABA Economic Perspectives, ABA Insider</i> Conferences: September 10-12, 2006

Target Audience	Channels	
IT Vendors	HIMSS Electronic Health Records Vendors Association http://www.himssehrva.org	Publications: Conferences: HIMSS Annual Conference February 25, March 1, 2007
	NHIN contractors	
Consumer Groups	AARP www.aarp.org	
	National Consumers League www.nclnet.org	
	National Health Council www.nationalhealthcouncil.org	Conferences: Voluntary Health Leadership Conference (invitational)
	AFL-CIO www.afcio.org	
	American Red Cross www.redcross.org	
	Families USA www.familiesusa.com	
	Kaiser Family Foundation www.kff.org	

Talking Point #1: This project helped clarify the importance of state-level HIE initiatives and the roles that can only be assumed by a state-level entity in creating an environment for collaboration, coordination and sharing of valuable information among stakeholders.

- State government is a stakeholder as a payer, employer, provider, regulator, and public health authority
- State-level HIEs can be the bridge between communities, neighboring states, and nationwide initiatives
- They can set HIE policy and standards, ensure alignment of laws and regulations, and reduce duplication of efforts
- They can provide HIE services or technical assistance and support to local entities that provide these services
- They can help catalyze health information improvements in state governmental agencies, a need that has not been widely acknowledged

Talking Point #2: State-level HIE initiatives differ significantly in their origins and drivers of action, state market characteristics, and approach. There is no single recommended model or one-size-fits all approach

- The Project Team advises against any form of mandate on state-level HIEs or any action that would lock in one particular approach
- A clear federal position in support of effective state-level HIE initiatives in each state would accelerate progress
- More effective channels for sharing lessons learned are needed

Talking Point #3: A number of barriers are shared by even the most experienced state-level HIEs. Major barriers include:

- Securing funding for start up, organization building and to sustain organizations over time
- Lack of consensus on the most effective role for state government in HIE and the silos within state governments
- Minimal participation and support from private payers
- Non-aligned stakeholder interests
- Lack of shared experience with start up projects that produce results
- No roadmap for how state-level HIE relates to federal NHIN programs or how contiguous states should relate to one another regarding HIE.
- Informal or insufficient mechanisms for knowledge sharing among state-level organizations

Talking Point #4: Recommendations for developing a state-level HIE initiative

- The Project Team compiled a set of guiding principles and planning worksheets and checklists that are presented in a document titled, "*State-Level Health Information Exchange Initiative Development Workbook.*"
- This workbook represents the Team's best advice at this point in time for developing organizations in the areas of governance, structure, operations, financing and health information exchange policies
 - A state-level HIE initiative does not have to tackle all activities at once, and there does not have to be consensus among all the stakeholders in order to move forward
 - Depending on how much HIE activity is already underway in the state and the history of collaboration between stakeholders in the state, the development process can be slow or fast

- Throughout this development process, it is important not to lose sight of the vision of sharing health information to the benefit of all

Talking Point #4: Recommendations for further research and development

1. Identify ways in which state-level HIE initiatives can directly support the federal health IT agenda and how federal initiatives can foster the development of sustainable state-level initiatives
 - Recommend establishment of a formal coordinating and communication channel among states and federal agencies. This coordinating body will maintain a current list of the concerns of state-level HIE initiatives and engage in constructive dialogue with federal agencies on solutions
 - Consider how the work of the American Health Information Community and the Office of the National Coordinator for Health IT can address the barriers that state-level HIE initiatives are encountering
 - Develop mechanisms to keep state-level HIE initiatives informed of relevant federal initiatives
2. Analyze the programmatic details of HIE projects that have achieved financial sustainability
 - Inventory and describe in detail HIE projects that have achieved financial sustainability and are successful
 - Recommend up to 7 different revenue models that are currently in use and have generated real savings/revenue & improvement

Background

- Most health care information today is fragmented and either on paper or held in electronic “silos” with little interoperability
- Fragmentation, in turn, results in errors, duplication, lack of coordination between providers, and many other problems
- It has also been concluded that major improvements will require the widespread application of information technology (IT) to provide physicians with immediate and effective access to both information about individual patients and current medical knowledge at the point of care
- The estimated savings in health care expenditures from the adoption of interoperable health IT and the secure exchange of healthcare information is quite significant

Goals of Health Information Exchange

- Significant improvement in the quality and safety of health care, increased efficiency and reduction in costs, facilitation of research, and enhancement of public health are the key end goals of the sharing of electronic health information securely between stakeholders, while protecting patient privacy

Project Overview

- This 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
- Leaders from the nine HIE initiatives, along with other subject-matter experts, convened to reach consensus on a series of practical steps to cultivate and build sustainable statewide HIEs in concert with nationwide efforts. The participating states were: California, Colorado, Georgia, Indiana, Massachusetts, Maine, Rhode Island, Tennessee, Utah

Project Goals

- To gather information from existing state-level HIE initiatives to determine successful governance, legal, financial and operational characteristics
- To develop consensus on guidance for developing state-level HIE initiatives
- To widely disseminate these findings
- In addition, ONC requested that the Project Team make recommendations on additional work needed that would benefit nationwide HIE efforts with particular emphasis on the role of state-level initiatives

About the American Health Information Management Association (AHIMA)

AHIMA is the premier association of health information management (HIM) professionals. AHIMA's 50,000 members are dedicated to the effective management of personal health information needed to deliver quality healthcare to the public. Founded in 1928 to improve the quality of medical records, AHIMA is committed to advancing the HIM profession in an increasingly electronic and global environment through leadership in advocacy, education, certification, and lifelong learning. For information about the Association, go to www.ahima.org.

About the Foundation of Research and Education (FORE)

FORE provides financial and intellectual resources to sustain and recognize continuous innovation and advances in HIM for the betterment of the profession, healthcare, and the public. For more information about FORE, go to <http://www.ahima.org/fore/>.

About the National Conference of State Legislatures (NCSL)

NCSL is a bipartisan organization that serves the legislators and staffs of the nation's 50 states, its commonwealths and territories. NCSL provides research, technical assistance and opportunities for policymakers to exchange ideas on the most pressing state issues. NCSL is an effective and respected advocate for the interests of state governments before Congress and federal agencies. For more information about NCSL visit www.ncsl.org.

About the Office of the National Coordinator for Health Information Technology (ONC)

The mission of ONC is to implement the President's vision for widespread adoption of interoperable electronic health records (EHRs) within 10 years. Appointed in May 2004, Dr. David Brailer, National Coordinator of Health Information Technology, serves as the principal advisor to the Secretary of Health & Human Services and ensures HHS' health IT policy and programs are coordinated with those of other relevant executive branch agencies. Dr. Brailer's office develops and maintains strategic plans to guide the nationwide implementation of interoperable EHRs in both the public and private healthcare sectors, helps coordinates health information technology programs and initiatives across the federal enterprise, coordinates all outreach activities to the private industry, and serves as the catalyst for healthcare industry change. For more information about ONC, go to <http://www.hhs.gov/healthit>.