## **Final Report**

## Synthesis of Lessons Learned in the First 5 Years of State and Regional Demonstration Health Information Exchange Projects

#### **Prepared for:**

Agency for Healthcare Research and Quality U.S. Department of Health and Human Services 540 Gaither Road Rockville, MD 20850 http://www.ahrq.gov

#### **Prepared by:**

AFYA, Inc. Clinovations ICF Macro

#### Authors:

Robin H. Pugh Yi, Ph.D. Anita Samarth Craig Dearfield, M.A. Jeremy Wong Andrew Gluck, M.B.A. Patricia Vazquez, M.A. Ajay Bhardwaj, Ph.D.

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# **Executive Summary**

## Background

In 2004, the Agency for Healthcare Research and Quality (AHRQ) established its Health Information Technology (Health IT) Portfolio as a mechanism to sponsor contracts, grants, and cooperative agreements that examine the impact of health IT implementation and its use on the quality, safety, and effectiveness of health care for all Americans. Between 2004 and 2005, among other initiatives, the portfolio funded State and Regional Demonstrations in Health IT contracts. AHRQ funded six States to identify and support data sharing and interoperability activities aimed at improving health care for patients and populations on a discrete State or regional level. These States and their respective health information organizations (HIOs) are listed below.

- Colorado: Colorado Regional Health Information Organization (CORHIO)
- Delaware: Delaware Health Information Network (DHIN)
- Indiana: Indiana Network for Patient Care (INPC)
- Rhode Island: current*care*
- Tennessee: Mid-South e-Health Alliance (MSeHA) (project management team from Vanderbilt University Center for Better Health)
- Utah: Utah Health Information Network (UHIN)

In June 2009, AHRQ awarded a contract to synthesize information about challenges and success factors these HIOs addressed in developing sustainable statewide or regional exchange of health information. The project yielded the current report, which presents narrative profiles for each of these HIOs and a synthesis of experiences and lessons learned.

## Methods

In September 2009, the AFYA research team met in person with representatives of the six HIOs to discuss a draft framework, a potential narrative profile, and synthesis topics. Participants voted to indicate topics they thought would be most useful to emerging health information exchanges (HIEs). The analytic team then conducted content analysis of HIO documentation, such as progress reports, meeting notes, and organizational charts to obtain descriptions of program goals, infrastructure, and operations. Researchers interviewed representatives from each HIO. Based on the results of document review, interviews, and discussions with HIO representatives, analysts refined focus topics to reflect input from HIO representatives. Results were analyzed to produce narrative profiles of each of the six HIOs. Analysts reviewed narrative profile results, as well as information learned during discussions among HIO representatives, to synthesize lessons learned and recommendations for emerging HIEs. Analysts conducted content analysis to identify themes from interviews, reports, and in-person meetings.

## Results

The AHRQ SRDs in health IT funding allowed the HIOs to take critical steps toward creating stable HIOs and establishing HIE. Over the course of the 5-year contract, they learned similar lessons while implementing projects with varied approaches and goals. In discussing factors that affected their success in achieving project goals and the lessons learned over the 5-year contract period, HIO representatives emphasized the importance of approaching HIE as a business operation. Lessons learned focused on the importance of project management skills, strategic planning, stakeholder engagement, business development, and ensuring responsiveness to community needs and concerns. Engaging community stakeholders, developing effective management plans, and planning for long-term sustainability presented the main challenges. All HIOs agreed that technical development, although challenging in and of itself, was the least challenging aspect of implementation and operations.

The following are key lessons that HIOs reported learning.

- Project Planning and Management: All HIOs determined that setting goals and defining the operational steps of achieving those goals was critical for success.
- Building Community Trust: HIOs agree that building community trust is accomplished through stakeholder engagement and addressing concerns about privacy.
- Project Implementation: Since policy and technical operations are mutually informative, HIE organizations should develop both simultaneously. HIOs agreed that it is essential for a leader with decisionmaking authority to define a concrete plan for progress and completion.
- Technical Considerations: The HIOs provided valuable information by testing different technical solutions. Areas for which continued work is needed include electronic Master Patient Index (eMPI) development and patient matching algorithms. New elements of the exchange must be technically tested and must meet business value criteria before they can be effectively implemented. Some HIOs developed specific methodologies for technical testing and business assessment that they applied to new capabilities and data types.
- Demonstrating Value: HIOs report that they demonstrate value most effectively when they present how the exchange decreases expenses of participating organizations and simplifies information exchange procedures. HIOs must discuss the value of participation in an exchange in a way that goes beyond simple monetary discussions. Saving money is an integral part of the value proposition; but a more comprehensive appeal for participation is necessary to promote participation in a regional or State exchange.
- Sustainability: Long-term sustainability requires a nuanced understanding of stakeholders' perspectives and priorities and the ability to present individualized value propositions based on this understanding. In addition, while HIEs may offer returns on investment across stakeholders, the savings may be diffuse. HIOs must develop value propositions that take this into account. Markets and technologies for HIE evolve rapidly

and vary across different regions. HIOs must focus on developing core ideas that can remain relevant in response to changes and variations.

HIO representatives agreed that the AHRQ contract funding was critical for implementation and system development. The 5-year term provided HIOs with the time necessary to gain an understanding of community and business stakeholders' perspectives and to develop policy and technical systems to meet their needs.

# Introduction

In 2004, the Agency for Healthcare Research and Quality (AHRQ) established its Health Information Technology (health IT) Portfolio as a mechanism to sponsor contracts, grants, and cooperative agreements that examine the impact of health IT implementation and its use on the quality, safety, and effectiveness of health care for all Americans. Between 2004 and 2005 the portfolio funded several initiatives, including State and Regional Demonstrations in Health Information Technology (SRD) contracts. AHRQ funded six States to identify and support data sharing and interoperability activities, health information exchange (HIE), aimed at improving health care for patients and populations on a discrete State or regional level. These States and their respective health information organizations (HIOs) are listed below.<sup>1</sup>

- Colorado: Colorado Regional Health Information Organization (CORHIO)
- Delaware: Delaware Health Information Network (DHIN)
- Indiana: Indiana Network for Patient Care (INPC)
- Rhode Island: current*care*
- Tennessee: Mid-South e-Health Alliance (MSeHA) (project management team from Vanderbilt University Center for Better Health)
- Utah: Utah Health Information Network (UHIN).

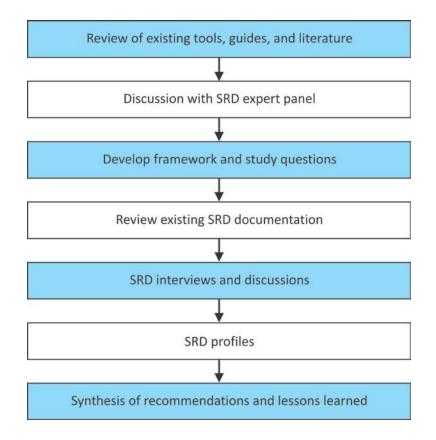
In June 2009, AHRQ awarded a contract to AFYA and its subcontractors, Clinovations and Macro, (AFYA team) to synthesize information about challenges and success factors these HIOs addressed in developing the sustainable statewide or regional exchange of health information. The project yielded the current report, which presents narrative profiles for each of these HIOs and a synthesis of lessons learned.

To focus data collection and analysis on current needs in the area of HIE, analysts conducted an environmental scan to assess the state of HIE research and development, and to identify available tools and resources. Results of this scan informed the approach to data collection. Analysts conducted telephone and in-person panel discussions with SRD HIO representatives to discuss the focus and framework for the environmental scan and data collection approach. HIO representatives recommended categorizing literature review results according to the five aspects of program functioning identified by the Office of the National Coordinator for Health IT: (1) governance, (2) finance, (3) technical infrastructure, (4) business and technical operations, and (5) legal/policy. HIO representatives stressed that, in their experience, current toolkits and guides do not provide enough detailed, step-by-step guidance about implementing HIE. HIO representatives noted there is a widely held perception among HIOs that their uniqueness restricts the applicability of toolkits and guides. They indicated that future toolkits and guides should address this perception.

<sup>&</sup>lt;sup>1</sup> Health information exchange (HIE) refers to data sharing activities. Health information organization (HIO) refers to an organization overseeing and governing the exchange of health-related information.

Analysts reviewed toolkits, guides, and literature for information gaps and current emphases in the field. This informed guidance regarding document additions that would be most useful to add to the current document repository on the AHRQ National Resource Center for Health IT Web site and would help determine the topics to focus on for synthesis of findings across the projects.

The following illustrates the process for collecting data and deriving the results presented in the current report.



## Toolkits and Guides Review

Analysts used Internet search engines, HIO Web Sites, and the National Resource Center for Health IT Web Portal to identify available tools and guides. Analysts scanned these materials to determine currently available resources and gap areas. Toolkits and guides are publications intended to inform HIE planning and implementation processes. They address a wide range of issues including policy frameworks, privacy and security, and technical architecture. Examples include Markle Foundation's *Connecting for Health* and Health Information Security and Privacy Collaboration's (HISPC) *Secure4Health* tools. These typically serve as conceptual frameworks rather than operational steps to guide policy and implementation. The environmental scan confirmed HIO representatives' observation that tools do not offer guidance through the decisionmaking process. A few legal agreements, policy and procedure documents, or sustainability plans have been published from individual HIOs. Efforts to provide more comprehensive legal agreements are currently underway (Rudin, 2009). For this project, analysts requested that AHRQ SRD projects provide any resources they had developed that provide concrete operational guidance. A consolidated repository or directory of HIE-related procurement documents, policies, and procedures will facilitate access to needed resources that currently have limited availability.

## Literature Review

Analysts scanned 100 peer-reviewed articles, evaluation reports, and industry publications published between January 2000 and August 2009. These were identified using Internet search engines and PubMed. The following section summarizes the types of information and key points found in the literature and indicates how the SRD narrative profiles presented here relate to current discussions in the field.

#### Governance

Governance structure is essential for ensuring accountability and effectiveness and for engaging stakeholders. Several publications provided descriptions of governance models and the responsibilities of governing bodies. Authors emphasized the importance of representing key stakeholder groups in HIE governance structures. Many emphasized the importance of involving the Federal and/or State Government in HIE efforts. Some articles discussed rationales for including specific stakeholder groups, such as State departments of health or consumers, and some provided recommendations for successful stakeholder engagement.<sup>1-7</sup>

The SRD narrative profiles presented later in this report describe governance structures and rationales, how governing bodies identified and engaged critical stakeholders, and experiences regarding developing and setting HIE governance mechanisms.

#### Finance

To succeed, HIOs must identify operational costs and potential sources of revenue. HIOs must demonstrate their value to potential sources of revenue if they are to become solvent. Lack of planning for long-term sustainability was cited as a major cause of HIO failure.<sup>8-24</sup>

This report summarizes SRD HIO key funding sources, business stakeholders, value propositions, and sustainability planning efforts. HIO representatives discussed experiences and recommendations in identifying potential revenue sources, presenting value propositions to their target communities, and developing plans to become sustainable.

#### Technical Infrastructure

Literature on technical infrastructure discussed the importance of achieving interoperability while protecting privacy. Authors discussed advantages and disadvantages of various data storage models as well as the role of reporting standards in interoperability. Each of these options was discussed in the context of resolving issues with exchanging data between disparate information systems.<sup>25-39</sup>

For this report, interviewers asked SRD HIO representatives to describe their system design and development, including technical architecture and rationales for key decisions in technological

development and/or vendor selection. HIOs also discussed their accomplishments in developing technical architecture, including issues with exchanging data from different organizations, the role of IT vendors in this process, and policies for accessing patient information.

### Business and Technical Operations

Publications discussing HIO business and technical operations emphasized the importance of defining the organization's mission and strategic planning. Several authors presented examples of HIOs that had failed due to poor planning. Some authors reported that political challenges were more difficult than technical challenges. Several articles presented principles for successful operations, such as building trust with the target community and ensuring that staff have critical skills.<sup>40-63</sup>

This report includes a review of SRD HIOs' decisionmaking and planning processes. HIOs discussed mechanisms that supported achieving their goals, and challenges they had faced in developing these mechanisms. Specific topics included discussions of how HIOs engaged stakeholders, essential staff skills, and how HIE has been adopted and used.

#### Legal/policy

The central legal/policy issues for HIE are protecting patient privacy and reconciling policies of multiple data exchange partners. Some authors discussed individual HIOs' approaches to privacy protection. <sup>64-74</sup>

SRD HIOs described the legal constraints their HIE had to address, any State-specific regulations that the HIO needed to consider, how their technical and policy infrastructures protect patient privacy, and how HIO representatives addressed community concerns about privacy.

#### Summary

Data collection efforts for the current project focused on SRD HIO experiences with critical aspects of HIE planning, implementation, and operations. In many cases, publications present concepts and principles with limited results of applying the principles in actual HIE. This report explores how HIOs used and applied these concepts and principles and collected HIO guidance and recommendations for future efforts.

# Methods

In September 2009, the AFYA research team met in person with representatives of the six SRD HIOs to discuss a draft framework, potential HIO profile, and synthesis topics. Participants voted to indicate topics they thought would be most useful to emerging HIEs. The table below presents a summary of the information HIOs initially recommended for descriptive information (e.g., research and synthesis from previous documentation) and for discussion with participants to develop narrative profiles.

<ul> <li>Descriptive Information <ul> <li>AHRQ Project Goals</li> <li>HIE Scope and Objectives</li> <li>Health Care Landscape</li> <li>Organizational/Governance Structure</li> <li>Organizational Partnerships</li> <li>Business Plan, Business Partnerships and Contracts</li> <li>Funding Sources</li> <li>Standards</li> <li>Data Exchanged</li> <li>Vendors/IT Systems</li> <li>Consumer Engagement and Patient Groups</li> <li>Alignment with Goals of National Initiatives (e.g., Healthcare Information Technology Standards Panel, Nationwide Health Information Network)</li> <li>Current Capabilities</li> <li>Future/Planned Capabilities</li> <li>Unique Characteristics</li> </ul> </li> </ul>	<ul> <li>Discussion Topics</li> <li>Initial Goals and Objectives of each project</li> <li>Planning Process</li> <li>Stakeholder Engagement</li> <li>Governance Overview</li> <li>State Regulatory and Legal Considerations</li> <li>Prioritizing Information to Exchange</li> <li>Staffing, Skills, and Resources</li> <li>System Design and Implementation</li> <li>Technical Architecture</li> <li>eMPI/Patient Authentication</li> <li>Patient Notification and Authorization</li> <li>Record Locator Service</li> <li>Adoption and Use</li> <li>Patient Engagement</li> <li>Provider Engagement</li> <li>Sustainability Plan Summary</li> <li>Next Steps</li> </ul>
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The topics voted most critical for synthesis across the projects were sustainability, engaging stakeholders, technology evolution, and adoption and use.

The above list guided document review and data extraction efforts. The analytic team reviewed existing HIO documentation, such as progress reports, meeting notes, and organizational charts to obtain descriptions of program goals, infrastructure, and operations. HIOs varied in their emphasis in these areas. As a result, HIO reports included varying levels of detail about the focus topics. For example, not all sought or received NHIN funding. Therefore, this was not a standard topic category for final SRD HIO profiles. Analysts extracted data from AHRQ SRD meeting minutes, progress reports, presentations, and other documentation submitted to AHRQ from 2005 to 2010 to create initial program profiles that were submitted to HIOs for verification and further discussion about focus areas for narrative profiles and synthesis.

Researchers scheduled interviews with representatives from each HIO, requesting that HIO leadership designate which staff should participate. The data extracted from the documents informed the specific questions asked of each HIO. Interviewers asked representatives to validate program profile information and discuss the following:

- Factors that led to implementation of their HIE, including responsible parties, resources used, and planning and decisionmaking processes.
- Structure and responsibilities of their governing board and key work groups.
- Staffing skills necessary for operations.
- Key stakeholders in the HIE and how the HIO engages them.
- Prioritizing data to exchange.
- System design and rationale.
- Legal issues in implementing their system.
- Sustainability planning.
- Critical lessons learned.
- Recommendations for emerging HIEs.

The research team joined scheduled SRD monthly teleconferences over the course of the contract to hear HIOs' discussions about accomplishments and challenges, to facilitate discussions about lessons learned and common experiences across HIOs, and to present status reports on the synthesis project. The team also attended a Capstone meeting conducted in May 2010, during which SRD HIOs discussed their experiences and lessons learned over the course of their contract period. The meeting provided opportunities to hear HIOs discuss topics such as project objectives and operations, value propositions, and governance structures.

Based on the results of document review, interviews, and discussions with SRD HIO representatives, analysts refined focus topics to reflect input from HIO representatives. For example, some HIOs indicated that they did not develop distinct approaches to provider and patient engagement during the contract period, but are increasing their focus in provider engagement as they near "go-live" or became operational. Most HIOs felt it was important to discuss approaches to engaging organizational stakeholders during HIE planning and implementation, and then focus on individual patients and providers. Several believed it would be more informative to discuss their technical development generally, rather than focus on the specifics listed during the September 2009 meeting. Some HIOs reported that Health Insurance Portability and Accountability Act HIPAA compliance was their main regulatory consideration. Each narrative profile includes health care landscape information as context for other topics. Based on results of the document review and discussions with HIO representatives, analysts developed narrative profiles for each HIO that include the following topics:

- "Go-live" date and data exchange volume (the metrics for data exchange volume (e.g., number of patient records, number of individual patients participating, number of clinical messages exchanged) varied across HIOs).
- Initial implementation and planning process.
- Key initial funding sources.
- Key business partners.

- Governance structure.
- Organizational structure and staffing requirements.
- Stakeholder engagement approaches.
- Prioritizing information to exchange.
- System design and implementation.
- Access to patient information.
- Provider adoption and use.
- Sustainability planning.
- Next steps for each HIO.
- Recommendations for emerging HIEs.

Results were analyzed to develop profiles of each of the six HIOs as part of the AHRQ SRD program. Following profile development, analysts reviewed results as well as information gathered during discussions among HIO representatives to synthesize lessons learned and recommendations for emerging HIEs. Analysts conducted content analysis to identify themes discussed during interviews, reports, and in-person meetings.

# Results

This section first presents a synthesis of findings and critical questions for the field, followed by profiles of each of the six HIOs.

## Synthesis of Lessons Learned

When the demonstration project began, the field of HIE was sparse and undeveloped. Available guidance and recommendations were minimal. There were few existing programs or vendors with in-depth knowledge or experience. The AHRQ demonstration funding allowed the organizations to take steps towards creating stable HIOs and establishing HIE. Over the course of the 5-year contracts, HIOs demonstrated different approaches to starting an HIE. Demographics, culture, care delivery infrastructure, and laws influenced the approach each organization took to establishing an HIE in its State or Region. The findings and lessons learned as part of the HIO funding can be leveraged for future HIE implementation, but specific program operations must be adapted to be responsive to the needs of each specific community served.

The AHRQ-funded SRD HIE projects demonstrated a wide range of approaches to HIE implementation. Over the course of the 5-year contract, they learned similar lessons while implementing projects with varied approaches and goals. The varied findings across these demonstration projects confirm that there is no single, uniform approach, checklist, or singular guidance that can be developed to direct the planning and implementation of HIE. Implementing the same technical architecture solution using the same approach and phasing in different communities will not necessarily have the same outcomes. Technology development influences policy and operational considerations, and vice versa.

In discussing factors that affected their success in achieving project goals and the lessons learned over the 5-year contract period, HIO representatives emphasized the importance of approaching HIE as a business operation. Lessons learned focused on the importance of project management skills, strategic planning, stakeholder engagement, business development, and ensuring responsiveness to community needs and concerns. Engaging community stakeholders, developing effective management plans, and planning for long-term sustainability presented the main challenges. All HIOs agreed that technical development, although challenging in and of itself, was the least challenging aspect of implementation and operations.

## Project Planning and Management

All HIOs determined that setting goals and defining operational steps toward achieving those goals was critical for success. HIOs recommend applying this work approach at project inception. Early planning stages involve significant conceptualization, discussing ideas and possible approaches to HIE. HIOs agree it is important for an HIE organization to start by clearly defining its own goals. For implementation to succeed, a HIO must transition from conceptualizing and discussing to assessing which approaches are feasible, then developing a concrete implementation plan.

HIOs recommend identifying a leader with strong project management and planning skills, understanding of technical and policy constraints, understanding of program goals, and

decisionmaking authority to guide system implementation. This person can guide the process of developing a plan for the project, as well as the implementation process. HIOs agreed that it is essential for a leader with decisionmaking authority to define a concrete plan for progress and completion. Typically, this person is the Chief Executive Officer or Executive Director of the HIO. Having a party responsible for monitoring progress toward implementation reduces the amount of time spent considering ideal solutions, which may impede moving forward at all.

## Building Community Trust

The HIOs report that establishing community trust is necessary for successful HIE implementation. They agree that this is accomplished through stakeholder engagement and addressing concerns about privacy, which are discussed in the following sections.

**Stakeholder Engagement.** It was essential to identify a broad range of potential data-sharing and other key business partners and to engage them to be invested in program success and involved in program decisions. This initiated business partnerships that ensured partner organizations felt a sense of ownership and had confidence that the HIE served their interests. Stakeholders provide a wide range of perspectives and contributions to decisions about HIE organization, policies, infrastructure, and operations. Another critical success factor for engagement is to keep participation costs as low as possible while still meeting stakeholder needs.

HIOs found it beneficial to initiate implementation in regions in which achieving the greatest clinical impact was easiest or required the fewest resources. Quick implementation helped HIOs to demonstrate the success of HIE. This builds community support and allows for the expansion of the exchange to other targeted regions. Informing communities of plans to expand maintained the regional focus of the exchange and built trust in individual communities. Once a significant number of providers in a region were sending data through the exchange, organizations that were not initially involved became motivated to participate. Some HIOs reported that it was valuable to work in several regions simultaneously or to inform the community that they planned to expand beyond initial target regions. This increased community support and avoided the perception that the HIE was intended to serve only part of the State or region.

A community's sense of engagement and ownership fosters trust in the HIE organization. Organizational mechanisms that allow target communities to voice concerns and address issues, such as privacy or types of data in the exchange, facilitate trust and participation. HIOs must consider all stakeholders' agendas and how each stakeholder is likely to value HIE implementation and participation. However, involving many different organizations sometimes made reaching consensus difficult. Participating organizations sometimes had opposing views and competing interests. In some cases potential data sharers' interests did not align with the HIO's. HIOs depend on data-sharing partners, with value of the system dependent on having enough data to exchange. They must place high priority on engaging potential data sharers who control access to significant portions of data. In cases where these organizations' interests compete with the HIE's or other key partners, including them in the planning process may result in project delays. HIOs are still learning how to address this issue. While key stakeholders may have agendas that conflict with the HIE, they are likely to be accountable to the target community for health care quality. The HIO may be able to coordinate with other community stakeholders to engage parties whose participation is critical for success. Some HIOs report it is critical to have staff that are skilled at facilitating and building consensus among disparate and competing stakeholders.

Factors that influence the effectiveness of stakeholder engagement approaches evolve with changing health care landscapes and technology. Currently, more providers use electronic health records (EHRs) than at the beginning of the SRD projects. The workflow changes necessary to participate in a regional or State level HIE, even if the practice or organization already uses EHRs, may prohibit that practice or organization from participation. Part of the benefit of participating in an HIE is that providers have access to more comprehensive information regarding their patients, but the providers must also be involved in discussions about who will access patient information and how it will be accessed.

The stakeholder engagement process has also shifted because of the recent Health IT for Economic and Clinical Health (HITECH) Act, enacted as part of the American Recovery and Reinvestment Act of 2009 (ARRA). Under HITECH, the Department of Health and Human Services (HHS) developed an incentive program for use of EHRs. As part of the Meaningful Use regulations, the Federal Government provides incentives to eligible providers and hospitals to implement, adopt, and meaningfully use an EHR. This funding goes directly to the provider or organization working to establish this EHR. Funding recipients use these EHRs to connect their own services, such as inpatient and ambulatory providers. This sometimes undercuts efforts to connect organizations via State or regional HIE. Meaningful Use requires the exchange of information between organizations, but does not specify participation in statewide or regional exchange. Some integrated delivery networks or hospitals are developing combined ambulatory EHRs that connect the ambulatory provider to the organization's hospital network to meet Meaningful Use requirements. However, some EHRs have limited HIE capacity. Some SRD representatives report that this increased organizational focus on implementing and deploying EHRs and HIEs is impacting the stakeholder prioritization of participating in State-level or regional HIE efforts.

**Privacy.** HIOs reported that seeking input from legal experts, patient advocacy groups, and other sources familiar with privacy concerns in data sharing was essential during the planning stages of the exchange. This input helped the HIOs navigate through State and Federal laws regarding privacy, and community organizations' concerns. The HIOs reported that an effective method for fostering trust in the exchange was to compare their privacy protection plans to their target communities' current protections and policies governing health data use. Demonstrating how their HIEs comply with HIPAA and other privacy policies helped HIOs to build community trust.

### Project Implementation

The HIOs report that focusing on either policy or technical planning processes, instead of both simultaneously, hindered effective and timely implementation. Since policy and technical operations are mutually informative, HIOs need to address both simultaneously. As implementation progresses, the HIO can adapt each to the changing environment. This is especially pertinent in this field since advances in technology and policy, including State and Federal laws regarding health information, regularly change the HIE environment. By working

on both policy and technical operations at the same time, an HIO can implement and establish exchange sooner.

HIO staff must interact effectively with the community. The HIOs report that a public relations or community liaison was necessary for implementation. These staff presented the benefits of joining the exchange to target communities. HIOs also report customer service or community liaison staff as an important part of community interaction. These staff members address concerns and answer the questions of participants in the exchange, including providers, physicians, and patients. Some HIOs found difficulties maintaining engagement and participation with national organizations, especially laboratories. These groups were not necessarily focused on providing services to one region and so were not as invested as regional health care organizations in the success of a regional HIE effort. However, other HIOs had marked success with such organizations. Market forces had an important part to play in this success.

After developing and implementing a system, a HIO must shift its focus to adoption and utilization. The HIOs reviewed in this report are currently making this transition, which involves learning what types of organizational support are necessary and what types of marketing are most effective and appropriate.

### Exchanging Information

Interaction with the community helps inform prioritization of the data to exchange and capabilities of the exchange. The HIO organizations suggest starting with an aggregated view of problem lists (e.g., diagnoses), medication history, allergies, and laboratory test results. Several HIOs report that discharge summaries, especially from the Emergency Department, and encounter notes and transcribed reports are important to some communities and comprise the next priority set of information to exchange via HIE. HIOs found that exchanging lab results was a challenge because it is sometimes difficult to secure participation from national laboratories (i.e., LabCorp, Quest). HIOs also noted that promoting the concept of a point-of-care (POC) query model is difficult until the exchange is sufficiently populated with data. Starting with clinical messaging responds to health care community needs for results delivery, populates HIE repositories, and sets the stage for developing POC access to HIE information. Once an HIO incorporates these types of information into a functional exchange, its focus shifts to expanding capabilities of the exchange, types of data involved, and its data senders.

The AHRQ SRD funding mechanism provided an opportunity for these HIOs to test options and approaches for technical architecture. When these HIOs started, most found that commercially-available technical solutions were unavailable or inadequate for providing a comprehensive and scalable HIE. Although the vendors and products available have matured, most HIOs report there is still no single set of commercially available technical products that can be purchased to address all the functions and capabilities necessary for an HIE. Available products require significant customization, and interfacing efforts remain necessary to implement HIE technical infrastructure. Others report that they are satisfied with commercially-available technical solutions and would pursue the same technical approach if starting today. The HIOs provided valuable insight by testing different technical solutions. They identified eMPI applications and patient matching algorithms as areas which require continued work. Several HIOs report challenges related to patient identification and matching, and it remains a subject for future work.

Some HIOs accepted data in any form, which required involving HIO staff to perform data mapping, translation, and transformation to standardize similar data within the HIE. They also had to develop their technical architecture to respond to all the types of data they received. These HIOs have programs and algorithms that may be used for future HIE efforts to address data standardization. Other HIOs required data senders to adopt their HIE interface specifications. This approach to HIE creates a standardized format that limits the need for data mapping, translation, and normalization. These organizations needed to develop a technical solution that allowed data senders to interface with the system.

Many of the HIOs started their exchange with fewer data types and capabilities than the exchange's current form. As exchanges stabilize and expand, HIOs can accommodate more types of data and capabilities. New elements of the exchange must be tested and must meet business value criteria before they can be effectively implemented. Some HIOs developed specific methodologies for technical testing and business assessment that they apply to new capabilities and data types.

Standards have changed since these SRD contracts began. At the start of the SRD funding, there were no standards for interoperability. As the HIOs worked to establish their exchange, they developed standards and adopted emerging national standards as they became available to work with the disparate organizations that agreed to share data.

#### **Technical Operations**

All HIOs found it essential to have a staff member who understood the scope and objectives of the project and who understood technical requirements for the project. Having someone with these capabilities on staff allowed HIOs to maintain focus on the goals of their project when dealing with technical vendors and products. The staff member did not necessarily need extensive technical expertise, but did need some degree of technical knowledge in order to communicate effectively with vendors.

The HIOs found that each type of technical architecture has its own set of advantages and disadvantages. It is important to know what works for the community to be served. Many of the issues that affected the implementation of a technical infrastructure were based on selecting the right set of technical specifications and vendors to complete the goals of the HIO. The software, hardware, and network capabilities were mostly already established. HIOs needed to compile them in a novel way to create a system capable of meeting their goals. This process highlighted the need for someone within the HIO to have an overall understanding of the technical system.

#### Demonstrating Value

An important part of expanding the reach of the HIE and developing a sustainability plan is to demonstrate the value of the HIE. HIOs must make a business case for their exchange. HIOs report that they demonstrate value most effectively when they present how the exchange decreases expenses of participating organizations and simplifies information exchange procedures. While many of the HIOs can explain how the exchange improves quality of care, without a business case, few organizations are willing to change their existing operating procedures. Several HIOs noted that they had strong operational support from institutional

partners while they established their exchange. This allowed an opportunity to demonstrate the system and take initial steps to test their business cases. It is important to have a sound business plan that addresses organizational business cases and demonstrates understanding of the HIE community's and stakeholders' interests.

Processes to demonstrate value and engage stakeholders have changed since these projects were initially funded. More providers use EHRs than they did 6 years ago. This has varying effects on HIE implementation efforts. In some cases, this may increase the chance of HIE success in a particular region since initial implementation costs and training time may be lower. Providers with EHRs may be more willing to participate in an HIE since they have already seen the benefit of an electronic system. However, with the expansion of electronic records systems, many health systems are building exchanges to make patient information accessible across care delivery locations and affiliated organizations. These health systems may have a decreased incentive to work with larger regional or State efforts since they already have an established system that serves similar functions. Integrating with State or regional HIE may present additional interfacing and integration burden and costs. Another potential disincentive is that EHR decision support capabilities in the market today do not extend rules and capacity to HIE data, making it difficult to make the longer-term quality value proposition for HIE.

The Meaningful Use incentives also affect how value is demonstrated. Because the Federal Government provides incentives to individual providers and organizations, HIOs must discuss the value of participation in an exchange with affiliated organizations in a way that goes beyond simple monetary discussions. Saving money is an integral part of the value proposition, but a more comprehensive appeal for participation is necessary to promote participation in a regional or State exchange.

#### Sustainability

HIOs indicate that an important part of developing a sustainability plan is determining which organizations and people benefit from HIE. This allows HIOs to negotiate payment for those services early in the planning process. The sustainability plan must develop from the capabilities and services of the exchange. Therefore, each sustainability plan for this set of HIOs is different. The sustainability plans must organically develop from the community and the exchange.

Initial goals stated in AHRQ proposals focused on quality improvement. While HIOs reported success in developing the technology and data exchange systems necessary to support quality improvement, they faced challenges in developing plans to sustain these systems. The value propositions necessary to support sustainability tended to be indirectly linked to broad quality improvement and did not readily deliver financial benefits to offset investments in the exchange. Rather, stakeholders based their investments on potential value to their individual interests. Long-term sustainability requires nuanced understanding of stakeholders' perspectives and priorities and the ability to present individualized value propositions based on this understanding. In addition, while HIEs may offer returns on investment across stakeholders, the savings may be diffuse. Individual stakeholders may realize only a relatively small return on their investments. HIOs must develop value propositions that take this into account.

Several HIOs report difficulty in transitioning from grant and contracts-based funding to a participant payment model. Other HIOs describe difficult negotiations with participating organizations that helped work toward the goals of the exchange without providing any payment. HIOs need to focus on providing services that stakeholders are willing to pay for from the outset. SRD representatives report that approaches for convincing beneficiaries to pay include presenting clear and concrete analyses that demonstrate cost savings, decreased errors, increased efficiency, and demonstrating how HIE participation does not present privacy or cost concerns beyond those associated with current systems for health data storage and exchange. Ultimately, the HIOs agree with the concept that those who benefit from the services provided by the HIE should pay for those services. Payment plans that have been suggested include charge per result, rate per adjusted patient day, discharge-based fees, and per member per month fees based on health plans.

The HIOs indicate that Federal and other outside funding is beneficial when establishing an HIO or implementing an HIE. Some HIOs reported that the terms of the AHRQ SRD funding allowed them to establish an exchange or expand the capabilities of their existing information exchange. The influx of financial support and the time to work on development and implementation allowed the HIOs to consider a wide range of approaches, learn from their experiences, and develop long-term relationships and strategies. Revenue from data sharing partners can provide operational sustainability once the organization and exchange have been established.

Participating HIOs noted that sustainability does not refer only to covering operational costs. Because of the difficulty in establishing a sustainability plan, none of the current HIOs report having fully achieved or implemented their sustainability model at this time; however, one AHRQ-funded HIO predicts achieving operational sustainability in 2011. HIOs must focus on developing sustainable ideas and processes. Markets and technologies for HIE evolve rapidly and vary across different regions. HIOs must focus on developing core services that can remain relevant in response to changes and variations.

### Staffing Requirements

HIOs identify the following essential staff skills as critical to successful HIEs:

- Project management.
- The ability to guide and negotiate technical architecture development based on the project's goals.
- Expertise in legal issues related to HIE.
- Customer service.
- Ability to liaise with clinicians.
- Ability to facilitate communication and build consensus.
- Marketing and media communications.
- Ability to engage stakeholders, particularly data contributors and users, advocates for patient privacy and other community interests, and data-sharing partners.

## Recommendations for Emerging HIEs

The HIOs recommend these actions be taken by emerging HIEs:

- Define their own goals in terms of serving community needs and developing their own identity as an entity distinct from participating partners.
- Assess feasible options and develop concrete implementation plans as early as possible.
- Understand key stakeholders' perspectives and priorities and engage them in HIE decisions to ensure they have a sense of ownership and investment in HIE success and have an opportunity to balance business interests with HIE participation.
- Identify data sources and data sharing partners whose participation will make data exchange useful and of high value.
- Set realistic expectations for quality and cost metrics.
- Assess system users' needs and how HIE is responsive to these needs.
- Clearly present the value of HIE participation to stakeholders and base long-term sustainability plans on value to users.
- Develop technical and policy infrastructure simultaneously.
- Ensure that all technical support details are thoroughly vetted and actively tested, including disaster recovery and business continuity practices.

### Summary of Key Themes

#### Importance of Demonstration Projects and Federal Funding

- There was minimal guidance 5-6 years ago on what works and does not work for HIE. These AHRQ HIE demonstration projects have contributed to this knowledge and to the market's maturity.
- Federal or outside grant funding is still needed to create a HIO and implement HIE. Ongoing participant revenue can support operational sustainability.
- Some of the most valuable learning and innovations were a result of unanticipated outcomes or implementations not going as planned.
- These projects confirmed that there is no one path to HIE. Demographics, culture, and care delivery infrastructure vary across regions and States; therefore, each approach to HIE will be unique.

#### Statewide vs. Regional Approach for HIE

- Local buy-in is necessary. When some or most regional providers start participating, peer pressure can help enlist others.
- If implementing a statewide approach, it can be effective to start in multiple regions simultaneously or communicate expansion approaches to build this regional support. Otherwise, an exchange can be perceived as being too focused on one region.

#### Evolution of HIE

- Vendors are developing their capabilities. There were few HIEs and HIE vendors in the market 6 years ago, and the SRD HIOs were venues for testing proof of concepts.
- There is no "HIE in a box." HIE products and solutions have greatly improved, but there are still gaps in functionalities and capabilities in many products.
- The value proposition and stakeholder engagement process are different today than 6 years ago:

   more providers have or use EHRs, and ARRA has motivated providers to participate or implement EHRs; and

- health systems are implementing their own HIEs to bridge their inpatient and ambulatory providers. These
  organizations may not be motivated to work with State/regional HIOs.
- There were no established interoperability specifications available when the SRD projects started. Standards
  have since evolved. Meaningful Use will require the ability to exchange clinical summaries to support HIE. The
  Standards and Certification Final Rule set content standards for a patient summary record to use either the
  Continuity of Care Document (CCD) or Continuity of Care Record (CCR).
- Most SRD HIOs reported significant challenges with vendor eMPI or patient matching algorithms and indicated that additional work is needed in this area.

#### Provider Adoption and Use of HIE

- After HIE is operational, expanding adoption becomes the most important focus. The AHRQ-funded HIOs are
  now focusing on adding organizational support to support implementation and use at practices, as well as
  marketing the HIE.
- Optimal utilization of POC HIE access has not yet been determined.
- An HIO cannot promote adoption of a POC solution until there are data in the exchange. This is why clinical
  messaging may be a good initial approach. It is a service that hospitals need and serves to populate the
  exchange.
- Workflow is a major component of HIE adoption in practices; yet it is often overlooked or underemphasized. Practices want to access patient information to optimize care quality; but it is often unclear who is responsible for accessing this information and how this should be accomplished. Practices need support in order to use HIE information within their workflow.

#### **Transitioning from Initial (AHRQ) Goals and Objectives to an Ongoing and Sustainability Focus** Aligning Benefits and Payments

- Stakeholder value discussions often lead to prioritizing information access (such as clinical messaging).
- It is difficult to translate quality improvement to cost savings or a sustainability model.
- In seeking payment, most SRD projects recommend setting an expectation from the beginning that stakeholders who benefit from participation pay for the HIE. It is difficult to obtain payment after data exchange has begun. This also drives the need for HIOs to focus on providing services for which stakeholders are willing to pay.
- It is difficult to make the value proposition for quality until the system is populated with data.
- The value proposition for HIE in the small practice environment is still elusive.
- None of the SRDs has a method for consumers to access their health information contained within the HIE. The value proposition for consumers has not been evaluated yet.

#### Achieving Sustainability

- Focus on sustainability needs to be part of initial planning for an HIE.
- Quality management, measurement, and reporting are viewed as value-added services that can be built after HIEs are operational.
- None of the SRDs currently report that they have already achieved sustainability; most are modifying their
  payment models to achieve this in the future.

• There is no defined path to sustainability; the approach needs to grow organically in each community. *Payment Models* 

- There is no singular payment model. Most SRDs are currently changing their payment models based upon their experiences from the demonstration project.
- Payment models vary, but include charge per result, rate per adjusted patient day, discharge-based fee, and per member per month (health plans).

#### Further Questions

The AHRQ-funded HIE demonstration projects have contributed valuable insight and contributed to the maturity of HIE solutions available today. They recommend continuing to ask some of the key questions that they addressed during the 5-year period and that remain for the field of HIE implementation.

- What are effective approaches to engaging key stakeholders whose business priorities may not align with HIE participation?
- Is there an optimal level of HIE utilization for improving care quality? Is there a level of utilization that results in financial benefits?
- How will the ARRA, especially the HITECH Act, affect the HIE business environment?
- What are the best practices for evaluating HIE's impact on health care quality, cost, and efficiency?

The following section details experiences from each of the six AHRQ-funded projects and provides further insight into the unique characteristics and findings of each HIE effort.

"When we started 5 years ago the challenges were unknown. Today there's a different set of unknown challenges. It's a dynamic process. Where do you go from here? Focus on the tools and the thinking that prepares for the next unknown ..." - Marc Overhage, Indiana SRD

# **Narrative Profiles**

Narrative profiles are presented for CORHIO, DHIN, INPC, Vanderbilt/MSeHA, current*care*, and UHIN. All results are current as of September 1, 2010.

## Colorado Regional Health Information Organization (CORHIO)

# September 1, 2010

Target Region: Colorado Target Population: approximately 5 million total in State "Go-Live" Date: December 2008 Data Exchange Volume: 2.6 million individual patients' data

### Initial Planning Process

CORHIO began as two discrete initiatives: the AHRQ SRD Project awarded to the University of Colorado Health Sciences Center, and a public community-based outreach initiative conducted by the Colorado Health Institute. These two initiatives merged in 2007 to create the private-public, nonprofit partnership now known as CORHIO.

The AHRQ SRD Project goal was to implement a point-of-care information exchange to be used primarily by emergency room health care providers. Four initial partners from the Denver metropolitan area were identified in the AHRQ contract proposal: Denver Health, Kaiser Permanente of Colorado, The Children's Hospital, and University of Colorado Hospital. The Public Health Informatics Leader at Denver Health served as the Principal Investigator. He convened the Chief Medical Information Officers (CMIOs) from the University of Colorado Hospital and The Children's Hospital, along with the Research Director for Kaiser Permanente of Colorado, to plan for statewide HIE. This group recruited more than 70 people from the four institutions and other private and public stakeholders to assist in the development of the project and to be involved with the planning and implementation process.

At the time of project inception, there were no standard models for sharing data at the point-ofcare. As part of the SRD contract requirements, Colorado SRD Technical Advisory Panel (TAP) was formed. The TAP comprised Chief Information Officers (CIOs) and CMIOs from the four data sharing partner organizations. Representatives of security, health information management, informatics, and medical and technical groups engaged in a series of extensive discussions, emphasizing policy issues and exploring potential system architectures for improving health care quality, as well as defining a manageable project that could show health care benefits. The TAP provided a forum for leaders from several institutions to discuss developments, strategy, and direction. Originally, there was no governance link between the CORHIO Board and the TAP. However, CORHIO has taken measures to integrate the TAP into its governance structure. Many issues and concerns arose during initial meetings of the TAP. Sharing health information had only recently been identified as a useful tool to improve care, and very few projects could demonstrate outcomes. This meant much of the effort's effects on the participants and users were unknown. It was also difficult to discern a potential return on investment for the participants. In identifying a technical infrastructure, the group sought to weigh the as yet unidentified risks and benefits to care, net financial costs and benefits, and liability. The participants also realized it was critical to identify and allocate staff possessing an overarching understanding of the proposed system and knowledge regarding the technical architecture necessary to support it, and who had the authority to negotiate and make decisions regarding system implementation.

### Initial Funding Sources

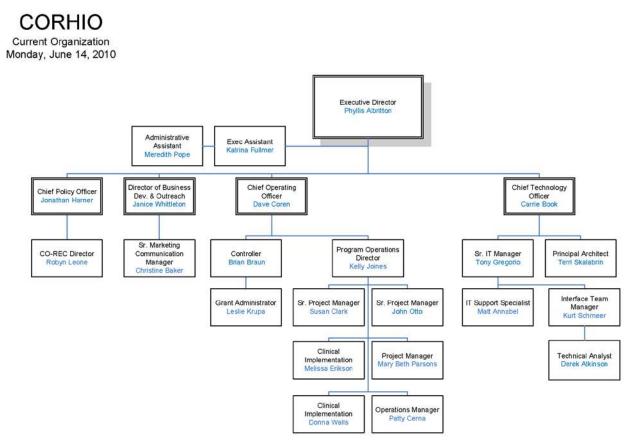
The Colorado Health Foundation provided initial funding to implement a HIE. CORHIO began to pursue additional National and local funding opportunities to begin its expansion of HIE across the State. CORHIO awards and funding sources have included those listed below.

- AHRQ SRD Contract (September 2004)
- The Colorado Health Foundation (2004, May 2008, June 2009)
- eHealth Initiative (2004)
- Colorado Department of Public Health and Environment's Cancer, Cardiovascular Disease, and Pulmonary Disease (CCPD) (Awarded January 2006)
- HISPC (2007)
- Governor's Building Blocks for Health Reform (April 2008)
- Office of the National Coordinator (ONC) State HIE Cooperative Agreement Award (February 2010)
- ONC Regional Extension Center Cooperative Agreement Award (February 2010)
- State Immunization Registry (pending)
- Fees from participating hospitals and physicians (planned)

#### Governance

CORHIO was incorporated in Colorado in March 2007, as a nonprofit entity. A board was established with by-laws to operate the corporation as a utility of service to the citizens of Colorado. Initially, CORHIO's governance structure reflected its focus on its four Denver-based data sharing partners. Since then, CORHIO has taken steps to expand participation to organizations outside the Denver Metro area. Currently, CORHIO's 23-member board of directors includes representatives from all four data-sharing partners as well as various Colorado health care stakeholders representing government, health care providers, insurance, consumers, and safety-net providers, as well as legal and business interests. CORHIO has worked to ensure broad representation from multiple stakeholder perspectives both public and private. The board leverages its knowledge and community networks to identify potential venues for presenting the CORHIO value proposition. Public partners on the board include Medicaid and the State Department of Health's Chief Medical Officer. It also includes quality organizations, employers,

consumers, hospitals, and other health care providers. CORHIO is a mechanism to transform health care rather than a technical project. Therefore, the board's scope is leadership-driven and not technical in its focus. The technical advisory committee provides guidance and support through its role as the technical arm of the board.



CORHIO's governance structure has evolved since inception. It currently includes four committees: audit and finance, technical advisory, outreach, and policy. These provide mechanisms for achieving consensus and collaboration with communities.

- The Audit and Finance Committee oversees the financial viability of the organization and is responsible for CORHIO's annual budget and fiscal policies.
- The Technical Advisory Committee, which includes more than 25 CIOs and other technical leaders from health care organizations across the State, serves as a venue for the community to offer advice and suggestions on technical topics, priorities, community readiness and collaborative support, and develop strategies to address technical barriers to HIE adoption.
- The Consumer and Outreach Committee offers advice and support regarding the needs of communities and various stakeholders and facilitates consumer input regarding HIE.
- The Policy Committee is primarily responsible for developing policies regarding HIE in the State and leads efforts related to the adoption, communication, and oversight of organizational policies and procedures.

The initial work of the Policy Committee was to modify the Markle Framework for the HIE in Colorado so that organizations could effectively exchange information. The Policy Committee developed this process in collaboration with the data sharing partners, as well as the State public health and Medicaid departments. The updated policies are expected to be presented and approved by the CORHIO Board of Directors in June 2010.

### Staffing Requirements

The initial data sharing partners contributed in-kind labor toward security, networking, data management, and legal compliance. Community stakeholders donated efforts toward establishing governance and policy. Available funding was not adequate to pay for these critical elements in establishing HIE.

CORHIO has identified the following staffing responsibilities as critical to its functioning:

- A technical expert with the ability to ensure that the technical architecture responds to community and policy needs and the authority to negotiate with vendors.
- An executive-level staff member with strong management and planning skills with the authority to make decisions regarding implementation.
- Sufficient staffing to meet the needs of each community from a clinical, as well as technical, implementation perspective either through direct services or through a vendor.
- Board and/or committee members who are aware of the community's health care landscape.
- Influential stakeholders who can facilitate positive community relations.

#### Stakeholder Engagement

A critical element of CORHIO's ability to implement data exchange as part of this demonstration project was the investment of its four data sharing partners, all leaders in the Colorado health care landscape. A CEO of one of the partners also served as a CORHIO board member and facilitated activities necessary to assure success. With a clear project

#### **Key Business Partners:**

- Denver Health
- Kaiser Permanente of Colorado
- The Children's Hospital
- University of Colorado Hospital

plan, deliverables and timelines, and additional CORHIO and third-party technical resources, the four partners began weekly technical meetings to build the message specifications and architecture, and develop user interface requirements for the exchange.

As CORHIO received funding after completing its demonstration project, the CORHIO CEO met frequently with communities around the State to discuss how HIE would support local community health goals for health care providers, including safety net and public health providers. Building community trust is an essential component for successful implementation of HIE. CORHIO's current governance structure is based on the concept that HIE benefits can be fully realized only when the entire community participates. As such, CORHIO emphasizes the need to assess and respond to the specific needs of each participant community.

The State approached the Colorado Health Institute (CHI), a nonprofit information clearinghouse, to act as a neutral party to convene stakeholders and facilitate engagement. Partners were concerned with how the exchange would benefit participating organizations and patients. Legal representatives were particularly concerned with the liability of their institutions.

CORHIO has been a member of HISPC since its inception in 2007. CHI was the fiscal agent for HISPC, which had synergistic goals of developing community partnerships and linkages. HISPC funding has supported CORHIO's focus on consumer education and engagement issues, as well as adoption of standard policies. As part of this initiative, CORHIO convened the four data sharing partners to develop and approve the exchange's master data sharing agreement, which was based on the Connecting for Health foundational documents. This agreement focused on issues related to exchange data's security and privacy.

### Prioritizing Information to Exchange

CORHIO's research indicated that Emergency Department (ED) physicians were often missing more clinical information than primary care physicians. Physicians treating adult ED patients identified previous electrocardiograms (EKGs) as the most critical information—due to its utility in evaluating patients presenting with chest pain. ED physicians treating pediatric patients identified radiographic images as the most critical data. Primary care physicians identified radiology reports, laboratory results, and medication history as priorities. As part of this process, CORHIO engaged technical experts at each partner site to determine the feasibility of exchanging each data type. Partners expressed concern with data availability and bandwidth limitations for exchanging radiographic images. Based on these findings and user survey results, data were prioritized in the following order:

- Radiology reports (top 25 LOINC codes)
- Laboratory results (top 100 LOINC codes)
- Medication lists and dispensing history
- EKG images and reports
- Registration information
- Aggregated problem lists

Through its community-based implementation strategy, CORHIO has directly engaged local laboratories to facilitate the exchange of laboratory results. CORHIO initially received data from participating institutions' EHRs, but has evolved to receive these data directly from local laboratories. Though national labs have not supported a regional or State HIE model of sharing results, CORHIO has made progress toward integrating them into the exchange.

CORHIO's Evaluation Report validated its original prioritization of data to exchange. User survey respondents expressed that radiology reports, laboratory results, EKG reports, and prescribed medications were very valuable. They also expressed that they would value data that were not yet available through CORHIO: discharge summaries, dictated procedure notes (e.g., echocardiograms, endoscopies, etc.), clinic/visit notes, and primary care physician and specialty

physician contact information. CORHIO has indicated that future implementation could include medication lists for all practitioners and better coordination of ED care in a medical home model. Medication information was also not always complete, as information was captured from hospital data sources and many patients do not fill their prescriptions at an in-house pharmacy (e.g., Kaiser Permanente patients, ambulatory prescriptions). CORHIO's point-of-care (POC) system experienced low utilization while operational, from December 2008 to October 2009. As a consequence, CORHIO has refocused its implementation efforts on clinical messaging. CORHIO believes that a clinical messaging model aligns better with its sustainability and data exchange goals. Clinical messaging provides more tangible value to its partners, while populating CORHIO's eMPI to facilitate future data exchange.

### System Design and Implementation

To adhere to the timelines of the project, and recognizing that 2 years had elapsed as CORHIO members explored architectural options and discussed other issues, the board needed to decide whether to build or buy a technical solution. After researching existing products in the marketplace, the TAP determined that an affordable, comprehensive, commercial solution was not available to address the real-time aggregation of data as described in the AHRQ project proposal. The TAP decided to proceed with building a solution. CORHIO recognized the exchange depended upon a robust system for patient identification. CORHIO conducted a cost and features analysis; and the Sun eIndex master patient index was selected as the tool for identifying patients. Since the Sun eIndex tool included a suite of products that could be leveraged for the exchange of clinical information, in addition to the master patient index, Sun Professional Services was contracted to build the solution.

CORHIO and its patient identity consultants, NextGate and Just Associates, devoted significant efforts and resources to the analysis, algorithm configuration and tuning, and data validation of the master patient index, while in tandem, Sun, CORHIO, and the partners established the connectivity and queries and HL-7 conformant message exchange. Partner interface engineers were responsible for ensuring that messages conformed to final CORHIO HL7 message specifications. This included building and sending test messages; modifying message organization and content; and collaborating with CORHIO software engineers to ensure data integrity and accuracy. During this process, CORHIO and its partners encountered challenges with the lack of specificity in HL7 messaging standards and interfacing with partners' EHR systems. Sun developed the user interface in an agile, iterative process, with short sprints of development under the direction and guidance of the CORHIO technical staff and clinical advisors. In addition, CORHIO held weekly policy meetings with health information management professionals and partners' security experts to define and agree upon the security and data sharing policies needed to proceed with data exchange.

The first critical implementation decision was whether the clinical data would be housed centrally at the CORHIO-operated data center, or continue to reside at the data provider facilities and be accessed using a federated model. Given participants' concerns regarding the new concept of sharing their data, CORHIO decided to go forward with the federated model, so that each participant's data would continue to reside in their own systems behind their own firewalls, and so that no clinical data would be stored at the CORHIO data center. Participants agreed to store demographic data centrally to facilitate the exchange. Code mapping is centrally maintained to

produce composite profiles of chronologic aggregated data on the 100 most common laboratory tests and 20 most common radiology reports.

A third-party vendor developed a proof of concept architecture. The vendor planned to develop the patient identification algorithm without utilizing a current commercial product. Ultimately, the TAP decided that the algorithm could not be developed in time to serve the needs of the exchange. So, CORHIO brought in a dedicated technical project manager to assess the status of the project and develop a plan for accomplishing the project's objectives, deliverables, and timelines.

CORHIO's eMPI establishes the basis of the exchange's record locater service (RLS). It is an identity management tool—automatically receiving, standardizing, and matching patient data across partner facilities. CORHIO maintains that a robust eMPI is a core component of HIE that determines how users access aggregated data. CORHIO believes that a critical component of maintaining eMPI accuracy is ensuring that data are corrected at their source rather than within the CORHIO system.

In September 2007, CORHIO began the initial phase of eMPI development during which partners provided images of their eMPIs for CORHIO to use in tuning its eMPI algorithms. Partners compared potential duplicates generated by their eMPIs to CORHIO-generated interfacility duplicates. The result was CORHIO's eMPI had 2.5 million records with 250,000 linked pairs when the HIE became operational in December 2008. Over the course of the development, testing, and production phases, CORHIO required more than 20 servers.

#### eMPI Demonstration

CORHIO plans to work with a commercial vendor to incorporate their experiences from the SRD project into implementation of the eMPI. This section highlights some of CORHIO's key findings regarding eMPI implementation for HIE.

# Importance of Demonstration Projects and Federal Funding Need for eMPI

The eMPI vendors did not have core competency in many areas that CORHIO needed. Some vendor solutions did not accommodate characters and patterns typically associated with medical record data such as hyphens, different first and last name order, and apostrophes.

#### Patient Matching

- To search patient records, users must input at least three search criteria or a patient's medical record number in order to limit both false negatives and false positives. If there are more than ten matches, the system informs the user that there is a potential match, but they must input more information.
- Though a Universal Patient ID (UPI) would be an optimal record-matching method—and effectively negate the need for an eMPI—a probabilistic matching approach is currently required as the basis for an effective RLS.
- Processing merges is a critical issue for HIEs. One of the differences between CORHIO's early eMPI work and other eMPI systems is fixing errors at the source, and not at the HIE. If the system cannot accept the merge at the source, the records will never be in sync.

### Access to Patient Information

CORHIO uses an opt-out consent model in which physicians inform patients about CORHIO during the clinical encounter and are able to gather opt-out information. It may take up to 2 work days for the opt-out information to be updated in CORHIO. Patients who have previously opted out are also able to opt back in during a clinical encounter with a participating provider.

CORHIO use agreements require that the system be used only in the context of direct patient care. Each partner also creates and manages user access policies. Prior to access, users must complete online training. Data sharing partners are responsible for activating and deactivating user access.

Ensuring that changes to HIPAA are reflected in CORHIO's policies—for example, recent changes regarding breach notification—has been challenging for CORHIO. CORHIO also has found it challenging to address State regulatory and legal considerations regarding sharing mental and behavioral health data. CORHIO believes this will be an ongoing challenge.

#### Adoption and Use

CORHIO's POC model experienced low utilization during its initial operational period and reports that stronger marketing, planning, and efforts were needed to promote the system to physicians. CORHIO found that approximately two-thirds of staff physicians and seven-eighths of resident physicians never logged into the POC system. Reasons for low utilization included time pressure in the ED; residents' site rotations coupled with the requirement that they use different logins at each site; and limited outreach to residents. ED physicians found the login and query process was overly time-consuming and password maintenance too cumbersome. Physicians expressed a desire for auto-population of EHR data; however, this was outside the scope of the CORHIO project.

CORHIO found that busy ED physicians were unlikely to seek additional patient information. The CORHIO RLS was used for less than 1 percent of patient encounters. Since ED physicians do not provide comprehensive care, they do not need the extensive information provided by a POC model. In addition, the system lacked certain capabilities that greatly affected provider usability, such as the inability to integrate patient search with partner clinical information systems and the lack of an automated password reset function. Given these factors, CORHIO leadership concluded that implementation in the ED environment would not provide enough clinical benefit to justify continued implementation.

Because CORHIO gave partners latitude in determining user access policies, it found that user types, data provided, and data retrieved differed considerably across partner sites. While three partners implemented the CORHIO system in their EDs, one partner had only call center users. Partners who implemented the POC system in the ED gave access to staff physicians, resident physicians, and "other staff." Two of these partners provided access to mid-level providers and nurses; one partner provided access to medical students.

The types of data provided by each partner site differed considerably. At one site, laboratory results and radiology reports were available in 80 percent and 60 percent of partner requests, respectively. In contrast, another partner provided minimal radiology, laboratory, and diagnosis

data, but medication history was available in 83 percent of partner requests (with a median of 5-6 medications available per encounter).

User survey data from CORHIO's evaluation report indicated the potential future benefits of CORHIO, as well as the shortcomings of the POC deployment. Respondents were confident of CORHIO's potential to improve decisionmaking, limit redundant testing, and improve efficiency of obtaining clinical information. Respondents indicated that CORHIO did not negatively impact patient care, though some interviewees worried that use of the system could lead to a less detailed exchange of information. Respondents also agreed that CORHIO's value would increase as data senders and types of data exchanged increased.

CORHIO has developed a proactive patient engagement strategy to explain its purpose and scope. CORHIO collaborated with a literacy specialist to develop 8<sup>th</sup> grade level reading materials to foster community support. While CORHIO originally intended to write this at a 6<sup>th</sup> grade reading level, legal advisors identified 8th grade as the lowest reading level that clearly communicates all critical information of concern to patients. Materials included a 3-minute informational <u>video</u>, which is available on CORHIO's Web site and was distributed in DVD format to consumers. It explains the benefits of HIE to patients and advises them to ask their doctors if they use HIE. CORHIO also developed a fact sheet, available in the six languages identified by participating hospital representatives as most used by their patients. Kaiser Permanente developed a brochure to inform patients about the capabilities of CORHIO and provide them with opt-out information. Kaiser distributed the brochure to 450,000 patients; only 100 patients requested to opt out.

#### Sustainability Planning

After low utilization of CORHIO during its operational period, CORHIO assessed provider needs for HIE. Results showed that clinical messaging was more beneficial than POC in most communities. As a result of these findings, CORHIO prioritized implementation of its clinical messaging system.

In December 2009, CORHIO completed the demonstration project and began evaluation of the production system. One of the key findings of the evaluation was the effectiveness of the master patient index at identifying patients within and across facilities. The master patient index served as an example of how HIE could assist in quality improvement efforts. This added to CORHIO's credibility with the community by providing a concrete example of the potential value of participation. CORHIO could now leverage legal documents and policies developed during the SRD project, in addition to the technical expertise gained during the project, as it planned for expansion of HIE throughout the State.

While operational, CORHIO's eMPI generated value to its data sharing partners by providing secondary identity management services, including generating intra-facility duplicate reports and inter-facility overlap reports. CORHIO's Evaluation Report revealed that partners found CORHIO-generated duplicate reports valuable. CORHIO also attempted to evaluate the utility of record overlap in ED use. Though approximately 30 percent of ED patients have an existing medical record number at a CORHIO facility, low utilization made it difficult to evaluate the value of this function.

In order for CORHIO to be sustainable, its board, based on the approved business plan, determined that results delivery was needed as a precursor to query functionality (i.e., POC functionality). In addition, a shift in the health care market had led to the availability of several commercial products with greater functionality than could be provided by the custom-developed solution. This led the CORHIO Board of Directors to recommend a request for proposals for a new technical infrastructure in early 2010 to support results delivery and a highly expanded services offering.

CORHIO believes that secondary identity management services create substantial financial benefits. CORHIO estimates that duplicate rates in single-facility eMPIs are 3-10 percent. Each duplicate record incurs between \$100 and \$400 in administrative costs and costs between \$6 and \$10 to correct. Large facilities also save by using CORHIO's eMPI rather than maintaining their own eMPIs. CORHIO believes that smaller providers, who typically do not have the resources to invest in patient identification tools, may realize even greater value from using COHRIO's eMPI.

Having fulfilled the demonstration project requirements, CORHIO began to focus on a sustainable business model. The contracted strategic consulting organization built a business model based upon the efforts of other successful HIEs around the country. The business plan defined the Colorado market and demonstrated lower cost and increased efficiency and accuracy if community providers used a common resource to exchange clinical data to improve care. The CORHIO leadership team solicited funds from the Colorado Health Foundation to facilitate the development of this common resource for all communities in Colorado that did not currently have HIE capabilities. CORHIO began to pursue additional national and local funding opportunities to begin its expansion of HIE across the State.

CORHIO's strategy is to enroll participants on a community-by-community basis, by medical referral region. CORHIO seeks to establish sustainability within each community, laying the foundation for State-level sustainability. Because its clinical messaging pricing structure will be subscription-based, expanding participation in CORHIO is a critical component to its sustainability plan. One challenge that CORHIO faced in determining a viable sustainability model was determining the costs partners incurred through support of implementing CORHIO. During the implementation phase of the demonstration project, partners were required to commit significant technical resources to ensure successful integration with the POC system. However, CORHIO has not determined the extent of the associated costs.

CORHIO plans to become revenue-generating within 2 years and fully sustainable within 3-4 years. Near-term tasks to support CORHIO's sustainability model include determining a pricing model for clinical messaging, effective eMPI vendor selection, and increased adoption.

#### Next Steps

The next version of CORHIO will exchange clinical messages as the initial step toward building the volume necessary for data queries or aggregation. CORHIO plans to deliver results in September 2010 in its early adopter community as part of CORHIO's strategy to implement HIE community-by-community. Health care organizations in Boulder, Colorado Springs, Northern Colorado, and Denver have signed letters of intent to participate. In keeping with goals set by the

CORHIO Board of Directors, CORHIO must support data exchange for 65 percent of Colorado's health care providers and users within the next 3–4 years. The board plans to recruit 85 percent of health care providers, representing seven medical referral regions, to exchange data at this time. CORHIO's strategy for reaching this goal is to continue presenting its value proposition to community stakeholders. CORHIO plans to use this approach to build HIE for each community.

### Key Lessons Learned

In addition to addressing the abovementioned staffing needs, CORHIO recommends that HIEs address these issues as well:

- Assess the needs and priorities of individual communities and coordinate with them to ensure HIE services are responsive to their needs and that the value proposition for HIE is relevant to the communities it intends to serve.
- Pay close attention to national standards and technical landscape developments so that the HIE maintains the flexibility necessary to address changing frameworks, priorities, and needs.
- Consider HIE implementation as an iterative process (early lessons should be analyzed strategically to inform further development and HIEs should plan how to leverage and reuse knowledge).
- Interact with other HIOs (CORHIO found that knowledge-sharing and interaction with other SRDs was an invaluable resource and similar communities should be established for emerging HIEs).
- Operationalize the steps necessary to achieve program goals and objectives at inception, and then continuously monitor feasibility and progress.
- Recognize that it is imperative to put a lot of faith in your vendors, but the vendor has to have the right resources to support the effort. Many vendor capabilities are still not able to meet the requirements of certain communities.

# Delaware Health Information Network (DHIN) Narrative Profile September 1, 2010

Targeted Geographic Region: Delaware Target Population: 885,000 (entire State) Initial "go-live" date: March 30, 2007—demonstration phase May 1, 2007—full implementation Data Exchange Volume: Total Volume: 15 million transactions/month More than 65% of Delaware providers (Medical Doctor, Doctor of Osteopathy, Nurse Practitioners, Physician Assistants) use DHIN as of 6/30/10. Over 85% of State lab transactions go through DHIN. More than 80% of State hospitalizations are reported through DHIN

# Initial Planning Process

DHIN was established by statute in 1997 as a public/private partnership with the mission of developing an electronic data exchange network to "promote the design, implementation, operation, and maintenance of facilities for public and private use of health care information in the State." DHIN's authorizing statute specified the composition of DHIN's Board of Directors. This included ex-officio State officials, appointees of the Delaware Health Care Commission, the State Medical Society, Delaware's hospital association, the Delaware State Chamber of Commerce, and individuals representing payers and consumers.

DHIN's original stakeholder group of hospitals, health plans, and physicians wanted to create an independent third-party electronic data interchange (EDI) network to facilitate streamlining of the payment process. The Delaware General Assembly initiated the Delaware Health Information Network to optimize methods for distributing patient information across the State while realizing greater efficiencies and lower costs and placed it under the direction and control of the Delaware Health Care Commission. By the time this legislation was passed in 1997, the large health plans had already started creating portals and other methods for EDI, so there was less of a need to create this type of network. A few pilot projects were initiated between 1998 and 2003, including one related to HIPAA. The concept of developing a clinical information exchange began to form in the early 2000s. In 2005, DHIN entered a strategic planning process. An environmental analysis was conducted to understand the clinical information exchange needs of stakeholders and the value proposition for participants. A technical committee looked at feasibility of different technical architectures based upon the results of the environmental analysis. DHIN's goals were to offer health care professionals across the State immediate access to more accurate and complete patient data at the point of care as a means to improve patient care, enhance communication among providers, and reduce medical errors.

DHIN aims to increase EHR system efficiency and value; while helping physicians without EHRs to better organize and retrieve test results for improved patient care. DHIN's ongoing goal is to engage 100 percent of those who provide health care to the citizens of Delaware.

From 1997 to 2003, the board worked to engage critical stakeholders without the benefit of dedicated project staff. This led to their hiring an outside management company in 2004, with the technical experience and project management skills needed to leverage the work done to date and to develop an implementation plan. In 2005, DHIN received its AHRQ SRD contract and leveraged this new funding to focus stakeholders, define measurable goals, and begin the implementation process. In 2006, DHIN received capital funding from the Delaware General Assembly's Joint Committee on Capital Improvements, which stipulated that State dollars must be matched dollar for dollar by the private sector.

In 2007, DHIN implemented a system that allows health care providers, including office practices, hospitals, labs, and diagnostic facilities, the ability to share real-time clinical information across the State. DHIN's vision is to improve patient outcomes and patient-provider relationships while reducing service duplication and the rate of increase in health care spending. DHIN serves as the intermediary between those who have clinical data and those who are authorized to view those data to support patient care.

In March 2007, DHIN became the Nation's first statewide clinical health information exchange.

# Initial Funding Sources

In addition to the 5-year AHRQ SRD contract, DHIN has received funds from other sources:

- State of Delaware (2006-present)
- ONC State HIE Cooperative Agreement award (February 2010)
- private sector matching funds for State funding
- NHIN funds for 1 year with 2 option years

DHIN receives its financial operation support in approximately equal proportions from Federal contracts (30 percent), State funding (35 percent), and private-sector funds (35 percent). Hospitals and laboratories contribute approximately 95 percent of private sector funding via transaction fees. The remaining 5 percent is from health plan grants.

#### Governance

The primary mechanism for receiving stakeholder input and guidance is through DHIN's committee structure. Committees do most of DHIN's work, with their responsibilities evolving as the system expands. Committees include the Executive Committee, Clinical Advisory Group, Consumer Advisory Committee, Project Management Committee, Health Information Management (HIM) Committee, Lab Standardization Workgroup, and Continuum of Care Workgroup.

- The Executive Committee provides strategic guidance to the Executive Director and acts on behalf of the Board of Directors when the Board cannot be assembled or as directed by the Board. The Executive Committee meets biweekly, has representation from each stakeholder group, and is the organization's primary decisionmaking body.
- The Clinical Advisory Group provides a forum for users to give feedback on DHIN policies, make recommendations for system improvements, and address barriers to DHIN adoption. Membership consists of clinicians and staff from private practices, federally qualified health centers, and hospitals that provide recommendations on system design and features and its applicability to clinical and practice workflow.
- The Consumer Advisory Committee provides the patient perspective input to the DHIN development, planning, and implementation. This committee is responsible for engaging consumers and ensuring consumer input on DHIN policies with respect to privacy, security, functionality, and consumer education. Additionally, the group has worked on marketing and educational materials for use in promoting the DHIN and assisted in design and content selection for consumer materials.
- The Project Management Committee consists of representatives from all the data senders and has broad responsibility for ensuring that the DHIN scope of work and project plan is achieved on time and with accuracy. This allows stakeholders to react to changes in the system, provide feedback on decisions and direction, and reach consensus on any outstanding issues.

- The HIM Committee provides guidance and oversight for ensuring the data integrity of information provided through the DHIN. The HIM Committee develops DHIN business processes to ensure the consistency of data management and master patient index integrity. Committee members provide guidance and input to the Project Management Committee regarding the impact of adding new functionality for existing DHIN data, as well as developing use cases and requirements for testing new data types and data sources.
- The Lab Standardization Workgroup provides guidance to the DHIN Technical Team on developing result and orders compendium standardization, implementing lab results trending and electronic lab test ordering, implementing lab code standardization (LOINC), developing policies and procedures needed to support the new lab-related functions, and developing test requirements and testing lab-related functionality. The members of the Lab Standardization Workgroup consist of the laboratory directors or related managers from all DHIN data sending organizations as well as the respective project managers.
- The Continuum of Care Workgroup focuses on long-term care and home health care needs, such as processes to communicate critical patient data at transitions in care. It consists of representatives from hospitals, home health agencies, long-term care facilities, and regulatory agency leadership.

DHIN's fundamental operating principle of the DHIN operations is that all stakeholders must agree as a group to move forward and smaller stakeholders have the same voice in the decisionmaking process as large stakeholders. As a public instrument of the State, DHIN is governed by all State laws regarding oversight and fiscal management.

# Staffing Requirements

DHIN contracted with its HIE vendor, Medicity, to perform IT staffing support during implementation and operations. Medicity also provides technical assistance for the development of new features and functions. During the planning and phase 1 implementation process, DHIN staff consisted of only a Project Director. DHIN has consistently expanded its staff to support growing operations.

DHIN has found the following staff skills to be essential to its functioning:

- Facilitation and consensus building among disparate and competing stakeholders.
- Strategic planning and continuous quality improvement.
- Marketing and media communications.
- Ability to relate with clinicians.
- Financial management, with an emphasis on sustainability planning.
- Strong project management skills.
- Ability to manage vendor relations and to collaborate with vendors to resolve issues.

# Stakeholder Engagement

DHIN began its planning process by conducting an environmental analysis that included feedback from more than 80 individuals representing physicians, consumers, hospitals, labs, radiology facilities, and government agencies. Since "going live" in 2007, DHIN has relied on the constant feedback of clinicians, consumers, and data senders to define its priorities and direction. DHIN publishes and distributes an electronic newsletter at least quarterly to all DHIN users and stakeholders. They use a secured Web portal to communicate with users about system and policy changes, as well as a public Web site to disseminate DHIN progress and status reports to the general public.

DHIN data receivers consist largely of community and ambulatory medical practices around the State, representing a wide variety of specialties and subspecialties. Community health centers and clinics, longterm care, home health, mental health and emergency

#### **Key Business Partners:**

- Provider Organizations
- Bayhealth Medical Center
- Beebe Medical Center
- Christiana Care Health System
- Nanticoke Memorial Hospital
- St. Francis Hospital
- Laboratories
- LabCorp
- Quest Diagnostics
- Doctors Pathology Services
- Hospital Labs from Participating
   Providers

Technical Vendor

• Medicity

Other

• Quality Insights of Delaware

department providers also use DHIN. New practices and providers are recruited to participate through referrals, networking at professional society meetings and events, and word-of-mouth. DHIN's implementation specialists are responsible for following up with practices, training users, and providing general customer service with the goal of getting practices to accept DHIN as their sole source for receiving all clinical results and reports. A key strategy for getting this "sign off"—DHIN as the primary source for the practice's receipt of clinical results and reports—is working with practice staff to configure DHIN to align with the existing practice workflow as closely as possible. Implementation Specialists train providers using their own practice's data.

DHIN's Consumer Advisory Committee is its major mechanism for consumer engagement. Since its inception in 2004, it has been deeply involved with DHIN's development and implementation. Membership of this committee includes representation from the Mental Health Association of Delaware, the National Alliance for Mental Illness, AARP, State Council for Persons with Disabilities, faith-based organizations, family caretakers, community health centers, and consumer health library services.

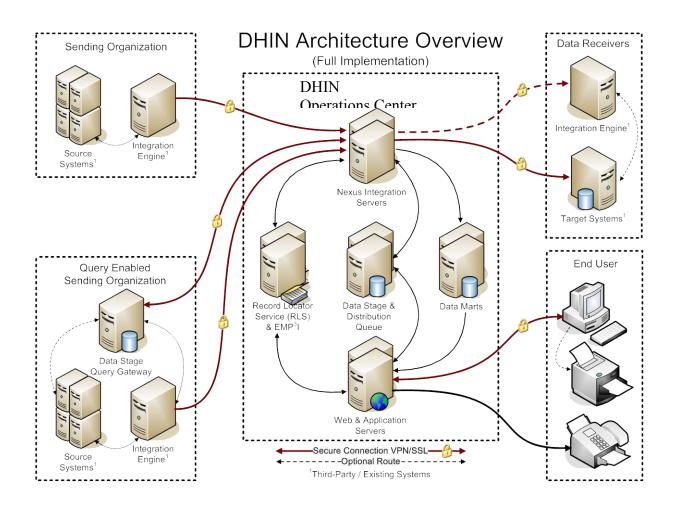
The Consumer Advisory Committee was also responsible for developing DHIN's privacy policy and procedures framework, as well as designing marketing, educational, and consumer materials to promote DHIN. DHIN's consumer materials are distributed to providers and include patient brochures and talking points to guide physicians' discussions with patients regarding DHIN.

# Prioritizing Information to Exchange

DHIN prioritized results delivery in ambulatory clinics because of the high rate of EHR usage (30 percent of ambulatory providers) in the State. DHIN believed that establishing data exchange among ambulatory providers was critical to affecting health care quality and cost in Delaware.

During the strategic planning process, DHIN conducted an environmental analysis to ask hospitals, practices, laboratories, radiology facilities, specialty groups, consumers, and government agencies about the type of information that would be valuable to them. Results showed that all parties wanted a way to increase the portability of health information and to deliver clinical results, especially laboratory results more quickly and securely. The original DHIN core data elements planned for exchange were extensive.

The initial focus on results delivery was based upon the needs and preferences expressed by hospitals and labs, which were willing to fund the system in order to streamline their current paper-based methods of results delivery. Once implemented, DHIN turned its focus on expanding its base of users and to implementing the patient search functionality. To accomplish this, DHIN narrowed an initial list of 15 core data elements, to five: (1) Patient Identification/Demographics, (2) Admission, Discharge, and Transfer (ADT) Information, (3) Lab Results, (4) Radiology Reports, and (5) Medication History.



# System Design and Implementation

DHIN used a strategic planning process to define a phased approach to implementing functionality. DHIN initially supported results delivery in 2007. In 2009, DHIN implemented the

community health record (patient query). Use of the system increased dramatically after adding the patient search capability. As of June 2010, more than 85 percent of laboratory transactions in the State and more than 80 percent of hospitalizations are reported through DHIN for secure results delivery and are available for patient search, by authorized users, of the community health record.

Through the strategic planning process, DHIN received feedback that stakeholders were not comfortable with a centralized data repository for data storage. As a result, DHIN issued a Request for Proposal (RFP) from vendors supporting federated data exchange models. DHIN received eight responses to the RFP and invited all stakeholders to participate in the vendor evaluation process. Three vendors were selected to participate in the second phase of the evaluation process. These vendors were given 2 weeks to prepare a demonstration of their products using DHIN data and DHIN's administrative and clinical test scripts. The administrative script focused on patient identification and results management (e.g., results forwarding). The clinical script focused on reports exchange (e.g., delivery of laboratory and pathology results, radiology imaging studies, and admission face sheets). DHIN also required these vendors to conduct a live "Web services call," during which vendors conducted a real-time query for patient information from a DHIN-affiliated health plan.

DHIN contracted with Medicity in September 2006 to provide the HIE core infrastructure, master patient index, and end-user access to enable statewide HIE services to providers. DHIN's beta "go-live" was on March 30, 2007 with statewide implementation on May 1, 2007, starting with results delivery. Public health reporting of chief complaint and lab information has been live since fall 2008. Patient inquiry providing access to clinical results and medication history was added 2 years after the initial "go-live," in June 2009, resulting in a dramatic increase in the use of the system.

Exchange capabilities currently include results delivery, transcribed reports, history and physicals, progress notes, consult notes, patient record inquiry to view the last 3 years of patient information including medication history, public health reporting (real-time reporting of data from hospitals to the Division of Public Health's Delaware Electronic Reporting and Surveillance System, DERSS), and admission face sheets.

For results delivery, the electronic health record (EHR) interface is configured to pull directly from DHIN. DHIN acts as the clinical messaging solution for its providers, which is seamless to the EMR users. DHIN has implemented Medicity's commercial product with minimum DHIN-specific customization and maintains a close partnership with Medicity to inform and collaborate on future product capabilities.

Results can be forwarded to other DHIN providers and users can also fax directly from DHIN. DHIN results delivery is accomplished via three methods.

• **Paper (Autoprint):** This method is designed for paper-based practices. DHIN results are routed to a networked printer in the practice and printed on a schedule determined by the practice (e.g., 7 a.m. every weekday).

- **Clinical Inbox:** This Web-based application is accessible to the practice through a Web browser. Inbox functionality includes electronic results delivery; remote access to data and reports; sorting and prioritizing messages; and real-time log tracking of results sent and received. Users can access patient results according to their preferences and sort results (e.g., unopened tests, abnormal results, by data-sender, by type of test). Users can also initiate a lookup query for a historical view of patient information. All DHIN users, including those who use Autoprint and a DHIN-certified EHR, can access results through the Clinical Inbox.
- **DHIN-Certified EHR Interface:** DHIN results can be delivered directly into a practice's EHR if the practice is using a DHIN-certified EHR.

Providers can customize the methods through which they receive results. They can also indicate which data they want to view for each patient. Implementation specialists follow validation procedures to ensure providers can view results through the interface they choose.

DHIN has contracted with Delaware's QIO (Quality Insights of Delaware, which also received a cooperative agreement to become Delaware's Regional Extension Center (REC)) to provide DHIN-EHR interface implementation support for physician practices.

DHIN has an EHR interface certification process through which standards-compliant EHRs can be certified to receive results via DHIN directly into the practice's ambulatory EHR. DHIN negotiates with certified EHR vendors on behalf of DHIN users to establish a competitive bidirectional interface rate and does not begin the integration process until a contract has been negotiated. The process of negotiating the contract between the EHR vendor and DHIN can take years to navigate and complete, as it is a State contract inclusive of indemnity and liability clauses and requires that vendors charge a single, reduced fee. Once the interface is complete, it is tested and validated at selected sites. After testing and validation, the EHR vendor can begin to sell the interface to providers as a DHIN-certified interface.

- Eight ambulatory EHR systems are currently certified. Additional vendors are in the process of attaining certification. EHR vendors were prioritized based on feedback from doctors, as the physicians in Delaware want EHRs with the DHIN interface.
- DHIN processes 15 million transactions per month and 13 million unique encounters per year. The eMPI has identified 650,000 unique patient records comprising the majority of patients in Delaware (2009 population was 885,000).
- To support laboratory results delivery, DHIN has facilitated electronic transmission of laboratory data among three hospital systems and LabCorp since 2007, adding a national partnership with Quest as well as the local laboratory, Doctors Pathology Services, in 2009; and another hospital in 2010. These results are transmitted through DHIN from the laboratories in real time.

### Access to Patient Information

Patient information is accessible to providers who have established relationships with the patient, such as the admitting, attending, copied to, referring, or primary care physician. A relationship must be established for a doctor to access any patient information. Results are pushed only for

patients with whom the querying physician has a relationship. In emergencies, physicians can "extend" a relationship to a patient's entire medical record using a multistep process that requires the provider to explain why s/he needs to view the information. This can allow access to an entire medical record. Only physicians can establish a relationship allowing continuous access (up to 6 months) to a patient's data. Other clinical staff can only obtain "one-time access" to a patient's information if they are authorized to do so and have a clinical need to know which must be stated upon a request for access to the patient "chart" in DHIN.

DHIN maintains a hybrid opt-out model. This means that patients may opt out of DHIN's query functionality through their physician by obtaining the physician's signature on the opt-out form, but cannot opt out of the results delivery functionality.

# Adoption and Use

As of March 2010, there were 2,559 users on the system, including 1,327 providers, which represents over 60 percent of Delaware's providers (physicians, nurse practitioners, and physician assistants). A total of 183 practices are live on DHIN; 37 are "signed off" and in the implementation process; and an additional 24 practices have completed the enrollment form and are awaiting set-up and training. A total of 20 percent of DHIN practices have designated DHIN as their sole source for clinical results/reports, indicating they no longer use traditional results delivery methods (e.g., mail, fax, courier).

DHIN's primary provider interactions occur prior to and during implementation. Once practices initiate the enrollment process, they are assigned an implementation specialist who supports the practice throughout the enrollment and implementation process, which includes training them using their own practice's patient data, rather than in a test or demonstration environment. Implementation Specialists continue to guide providers through the process of results delivery, focusing on workflow redesign, customizing delivery rules (result types or data senders that the provider prefers to see), and validation (ensuring providers can view all results thorough the Clinical Inbox and/or Autoprint). For practices seeking a direct interface with DHIN from their EHR, the Implementation Specialists coordinate with Quality Insights of Delaware to provide technical support to the practice to ensure the interfaces are functioning properly and appropriate validation of the clinical data in the EHR is achieved.

DHIN has performed very limited direct marketing to providers and has thus far mostly relied upon passive marketing approaches such as conferences, professional society meetings and events, and word-of-mouth marketing to publicize the exchange among providers. DHIN is now increasing its focus and resource allocation to provider outreach and marketing. DHIN staff do not report resistance or concerns regarding the accuracy of information, but have noted three types of resistance from participants: (1) provider resistance to transition from a paper to electronic workflow; (2) resistance from administrative staff (in practices where the physicians are supportive) who believe DHIN is trying to fix a system or workflow they believe is not broken; and (3) provider resistance for clinical workflow reasons, such as hospitalists who do not want to see information other than what they have ordered since they only manage a patient for a defined period during the hospital stay.

# Sustainability Planning

DHIN is funded in roughly equal parts by Federal, State, and private funds. DHIN data senders are responsible for most private funding. Each funder expects a return on investment through improved quality of care, increased patient safety, and decreased costs. Demonstrating value in this way depends largely upon maximizing use of the system to deliver clinical test results and reports, and using the patient query tool to avoid duplication of efforts, improve coordination of care, and reduce risk to the patient.

Currently, data senders finance the private sector proportion determined as a proportion of data senders' transaction volume. However, DHIN is developing a payment model in which other stakeholders will contribute to the exchange and intends to charge participants value-based fees. DHIN's long-term sustainability plan relies on increasing the percentage of results being delivered to participating practices and distributing the cost of maintaining the system among data senders and health plans accordingly. DHIN has increased its focus on capabilities that are part of Meaningful Use, such as electronic order initiation, structured data, continuity of care (summary record) exchange, medication reconciliation, patient notification, public health reporting, etc.

#### Next Steps

The Delaware General Assembly passed a bill in June 2010, which amends the DHIN statute changing it from an instrumentality of the State to a State Corporation. The law, which takes effect on January 1, 2011, maintains the liability protections and ties to the State budget and creates a public-private partnership outside of State government. Additionally, the bill gives the Governor the authority to appoint the DHIN Board of Directors with input from the DHIN and its stakeholders.

In 2010, DHIN expects to add additional features and functions:

- Allowing users to order lab tests through DHIN from their EHRs;
- Coordinating with the State Department of Public Health to develop a statement of work allowing for connectivity with the immunization registry so that DHIN users can retrieve immunization records and report immunizations administered;
- Supporting transcribed clinical reports delivery and viewing from the hospital data senders; and
- Adding Medicaid as a data sender for encounters, medications, patient eligibility, and provider information for enhancing the current DHIN statewide provider directory.

DHIN is continuing to add data exchange capabilities based upon feedback from its stakeholders, advisory committees, and workgroups, including the following efforts that are in progress:

• Radiology Images: DHIN is completing testing for radiology image exchange in which an embedded link is included in the radiology report to allow authorized users access to Picture Archiving and Communications System (PACS) images at the source system via single sign-on.

- Medication History: In February 2010, DHIN began a demonstration of medication history functionality using a third-party aggregator of pharmacy information that is not yet available to all users.
- Transcribed Reports: DHIN implemented transcribed reports exchange, including Progress Notes, History and Physicals, and Consult Notes.

## Key Lessons Learned

In addition to the abovementioned staffing needs, DHIN recommends the following to emerging HIOs:

- Planning is a necessary first step to HIE. Without clear requirements and an implementation plan, success cannot be measured.
- Strong and effective leadership is a key success factor.
- Selecting the right vendor is critical to success. The HIE infrastructure must be reliable, available, and scalable to ensure participants' needs are met.
- Using approaches such as beta testing to allow systematic assessment of full functionality before implementation is key; first impressions are critical to maintaining participant satisfaction.
- Building consensus among stakeholders ensures the ability to work with all data senders, regardless of size, to provide a unified set of services to DHIN users, which is critical to success.
- Board members must be responsible for ensuring that the HIO's direction and priorities are viable. It must be clear that the board members represent the HIO's interests rather than the organizations by which they were appointed.
- The greatest challenge for HIE is not technical implementation, it is to effectively engage stakeholders and build a sustainable business model.
- HIOs should operate like an efficient business and understand that private industry will move fast to compete in the marketplace.

# Indiana Network for Patient Care (INPC) Narrative Profile

# September 1, 2010

Targeted Geographic Region: Indiana Target population: 6.4 million (entire State) Go live date: 1995

Data exchange volume:

- INPC has over 20 million unique patient registrations representing over 10 million unique individuals
- IHIE has over 19,000 providers (in 5,400 practices) receiving data via clinical messaging
- Over 36 million results delivered

Participant organizations: 66 hospitals, 20-facility long-term care group, 2 national laboratories, 2 imaging center networks, 3 health plans

Clinical repository data:

- 20 million registration events (encounters)
- 41 million orders
- 1.5 billion coded results
- 25 million text reports
- 9 million radiology reports
- 12 million drug orders
- 750,000 EKG tracings
- 140 million radiology images

# Initial Planning Process

The Indiana Network for Patient Care (INPC) was started by the Regenstrief Institute in 1994, before HIE was a formally recognized field. INPC was in operation prior to award of the AHRQ SRD contract. Its focus was to solve the problems of clinicians who had incomplete patient data. Patients were often seen by physicians in an emergency care setting (for example) without critical data about their condition and treatment. Regenstrief researchers recognized a need to bring usable information to clinicians at the point of care and designed INPC to be a solution for providers. INPC was developed in collaboration with 27 data sharing partners representing hospitals, practices, community health clinics, and homeless care sites. Initial features included a secure wide-area network, a clinical data repository, and software to enable a cross-institutional combined view of an individual's medical results.

In 2003, Indianapolis business community leaders commissioned a report from Battelle to identify priority focus areas for business development. The report indicated that life sciences should be a priority. In response, a new organization named BioCrossroads® (www.biocrossroads.com) convened work groups that determined that health IT should be developed in Indiana. Based on these recommendations, BioCrossroads commissioned the Boston Consulting Group to conduct a study on the most effective way to develop and implement health IT in the community. In 2004, Indianapolis civic leaders created Indiana Health Information Exchange (IHIE), a nonprofit organization, to provide technical support and help INPC to develop a sustainable business model.

Since 1994, the INPC system has evolved and expanded while maintaining its original focus and priorities. INPC first facilitated data exchange within a single hospital system. As of August 2010, over 19,000 clinicians across the State of Indiana exchange data through the system.

## Initial Funding Sources

In addition to the 5-year AHRQ SRD contract, over the past 5 years INPC has received other funds, including NHIN contract funds for 1 year with 2 option years, AHRQ "Transforming Healthcare Quality through Information Technology" grant funding in 2004, and National Library of Medicine Integrated Advanced Information Management Systems (NLM IAIMS) operational support.

#### Governance

Three entities, the Regenstrief Institute, IHIE, and the INPC Management Committee, are responsible for HIE operations. IHIE is a nonprofit 501(c)3 organization that is governed by a board of 16 organizations representing major stakeholders in Indiana. IHIE is the service provider that works to expand the reach of currently available services, providing customer support, business development, technical resources, and physician liaisons. IHIE also is responsible for identifying potential sources of capital and assessing the feasibility of potential use cases, with emphasis on identifying the value of participation for different stakeholders. Regenstrief Institute is responsible for INPC's research and development technical direction, implementation, and operations, including application and technical support. The INPC Management Committee sets rules about data use and serves as the primary governance group. The management committee is composed of representatives from the organizations participating in the INPC and the Regenstrief Institute. They assess whether potential uses are in the patients' best interests and determine the constraints on how data will be used. In addition, IHIE operates the following committees that serve as advisory groups for the exchange.

- Steering Committee provides general oversight of the clinical messaging project. Focus is on new functionality, issues, and problem resolution. Membership includes CIOs from the charter member hospitals and representatives from IHIE and Regenstrief Institute.
- Application Committee provides for the development of community standards, creation of acceptance testing plans, development of training materials, implementation of physician offices, and development of application enhancements. Members are from the interface teams at each of the charter hospitals; they are involved in the day-to-day operations of the clinical messaging service.
- Strategic Planning Committee identifies and evaluates potential research and other projects on which IHIE and Regenstrief can collaborate. Membership includes executive staff from IHIE and Regenstrief, as well as key project personnel from both organizations.
- Security Committee provides updates to the security enhancements of the clinical messaging systems. HIPAA issues are reported to Security Committee members for resolutions. Members include security and privacy officers from each of the charter hospitals.

# Staffing Requirements

INPC/IHIE identifies the following staffing skills as essential to its functioning:

- Support and training for end users.
- Technical operations capabilities (INPC leaders recommend that HIEs do not need to build their own technical products, but do need staff with technical operations capabilities).
- Ability to map local data to standard codes.
- Strong project management skills.
- Legal expertise, especially regarding privacy.

### Stakeholder Engagement

INPC leaders describe their growth as organic. They respond to the needs of clinicians and data providers, expanding reach and services incrementally. Since INPC's core HIE infrastructure has been operational for many years, its focus is on expanding participants (both data senders, and ambulatory providers), and the development of value-added services for the provider community.

#### **Business Partners**

- Regenstrief Institute technical direction, implementation, operations
- Indiana Health Information Exchange service provider
- Public Health and INPC participants
  - Indiana State Department of Health
  - Marion County Health Department
- Indiana University School of Medicine (local public academic institution)
- BioCrossroads (local public life sciences organization)
- Founding Hospital Systems and Physician Practice Groups
- Indiana University Health (formerly Clarian Health)
  - Community Health Network
  - St. Francis Hospital and Health Centers
  - o St.Vincent Health
  - Wishard Health Services
  - Indiana Clinic (formerly IUMG-PC)
  - Several other hospitals and physician practices have become partners since INPC's founding.
- Community Participants
  - Central Indiana Corporate Partnership
  - o City of Indianapolis
  - Indiana State Medical Association
  - Indianapolis Medical Society
- Pharmacy dispensing Surescripts (data sharing)

INPC evaluates each change in their organization, such as adding a data type to the exchange, for its business value proposition. They evaluate aspects of the change such as how many patients

are affected, what organizations need to be involved, how to implement the new service, and how much it will cost. There have not been changes in this approach since inception. Regenstrief and IHIE engage clinicians and health plans by contacting them to present their business case. For example, the potential savings offered by Quality Health First (QHF) is one of the major reasons payers have engaged. Because of the community priority on life sciences and health IT, many potential participants have existing collegial relationships which facilitate willingness to participate. Other factors that facilitate interest in participation are INPC's cost-effective solution for results delivery and increasing interest and investment in health IT across Indiana. INPC notes that its relationships have been built over a long time. They use the services of BioCrossroads to help facilitate discussions among stakeholders. Participants are often aware of and communicate with an organization for a long time before they participate. For example, members of the nursing home industry have been in discussions with INPC for 5 years. The first nursing home signed a participation agreement in spring 2010.

## Prioritizing Information to Exchange

INPC indicates that the highest priorities for data exchange among its stakeholders are lab, radiology, and ADT data. By 2004, all INPC institutions had committed to providing radiology reports, discharge summaries, operative notes, pathology reports, medication records, and EKG reports as their minimum contribution to the INPC.

INPC based decisions about prioritizing services on its phased approach to infrastructure development. Each phase was financially self-sustaining and offered multiple services to multiple stakeholders. Based on this approach, INPC offered services in the following order: clinical repository services, clinical messaging, and clinical quality services. If starting from scratch, INPC indicates that beginning with clinical messaging might be a better starting point. INPC has initiated discussions with pharmacy benefit managers and payers about their interest in an incremental approach to e-prescribing. The initial step for this approach has been the INPC delivers a printed medication history synthesizing data from multiple medication sources.

# System Design and Implementation

The major goal of INPC is to extract data out of silos within participant organizations and establish trust in the community so that the data can be aggregated and accessible to providers. INPC's architecture is designed to support and facilitate data use and re-use.

To facilitate participation and engagement, INPC strives to keep technical architecture simple. The INPC system stores data in a federated model, with all data physically residing in a central location. Data are physically separated by originating institution, but operate in the same software system. Messages from many source systems flow into one centralized facility, where INPC staff develop routines to standardize the HL7 messages, map local observation and report codes to a universal standard, and link multiple patient and physician identifiers for one individual to a standard identifier.

The INPC system matches patients within and across institutions. The current patient-matching infrastructure requires a patient identifier or medical record number assigned by a known registration authority to be associated with results. A deterministic matching algorithm links multiple records for one patient. INPC maps local laboratory, radiology, and drug codes to

universal standards. Mapping to a common code system allows INPC to consolidate patient data for use in decision support, public health, and research.

INPC's perspective is that data can only be leveraged for use and re-use if represented in a standard format. Therefore, supporting use of Logical Observation Identifiers and Name Codes (LOINC®) and RxNorm were central to INPC's early work. Regenstrief developed, maintains, and supports LOINC for laboratory observations. The National Library of Medicine (NLM) developed RxNorm as standard nomenclature for medications.

INPC maps all institution laboratory codes to LOINC. Mapping laboratory codes is particularly challenging due to the large number of distinct tests per laboratory (typically 2,000–4,000) and the short, often nondescriptive test names. Mapping requires significant manual effort—ranging from a few person-days (for common EKG systems) to 12 months (for large laboratory services). INPC has found that a small number of laboratory tests account for a large number of total tests. Prioritizing the over 45,000 LOINC codes by frequency significantly decreases the mapping burden. As of May 2007, 80 codes accounted for 80 percent of tests; 784 codes accounted for 99 percent of tests. Radiology code-mapping is less laborious since there are typically 600–1,500 tests per facility and test names tend to be longer and more descriptive.

INPC has found that to-date, the capability of EHR and HIE systems to import and export a continuity of care document (CCD) is available or increasing, but CCD use remains limited. Most systems are not able to use the data contained within CCD. They are not designed to extract or store the CCD's structured data within the EHR that is available for decision support. For example, one of the INPC participating hospitals tried exchanging CCD documents, but reverted to exchanging PDF documents because it was not ready to use structured data.

#### Medication Hub Pilot Project

As CMS rules for e-prescribing standards were being promulgated, Regenstrief developed the Medication Hub Pilot to define the role that a medication history service could play. This hub is also used by Vanderbilt University through the Mid-South e-Health Alliance (MSeHA) to test how another HIE could send messages and receive information from the hub and leverage the infrastructure built by Regenstrief. A third site, Suburban Hospital in Bethesda, MD, was added in February/March 2009. This pilot tested the overall concept of a distribution node to reduce the number of interfaces that a source of medication history like Surescripts® must support for clinicians, pharmacists, and patients. The goals for this project were to evaluate the issues below.

- What are the technical, policy, and financial requirements for and barriers to an open-source medication history?
- What are the limits of this approach?
- What are the costs?
- How can a medication hub serve as a utility for others?

Surescripts was an obvious source for medication history data, but the project team identified the need to integrate information from local payers that do not participate in Surescripts, such as local pharmacies. The medication hub started with pharmacy benefits management (PBM) data from Superscripts and then went live with retail pharmacy data in February 2010. The hub is also receiving medication lists from some NextGen EHR users.

Two different models for providing the data have been implemented. The model used by Regenstrief and Suburban Hospital pushes information to the provider. In this case, providers get data 2/3 of the time and do not view the information the other 1/3 of the time. In the model employed at MSeHA, providers need to actively request medication history information. MSeHA pays for the cost of each transaction requested.

Vanderbilt found that about 40 percent of patients had medication information within Surescripts. Although Tennessee's Medicaid provider (TennCare) was on the Surescripts network, there were still PBMs that were not on the network.

Multiple medication history lists that may differ from each other are available from various sources and systems such as EHRs, e-prescribing systems, payers, and HIEs. The pilot projects generated discussion on the need for a consolidated or reliable source for medication history.

The INPC system delivers three basic services: DOCS4DOCS®, the INPC Clinical Repository and Results Viewer, and Quality Health First of Indiana®.

**DOCS4DOCS.** An important turning point in INPC's evolution was developing the DOCS4DOCS® report delivery system. When INPC first began exchanging data, they used a "pull" model offering a comprehensive view of patients' records at the point of care. In 2003, INPC learned that clinicians would not always look up data and wanted a "push" model. Regenstrief responded by developing DOCS4DOCS, a clinical messaging service which sends text reports such as laboratory, radiology, transcriptions, and cardiology, from source systems at hospitals and delivers the information to affiliated providers. DOCS4DOCS provides three methods for physicians to receive or access clinical information from participating organizations:

- Secure Inbox—the DOCS4DOCS portal is a secure, Web-based "inbox."
- **Direct EHR Integration**—clinical messages can be delivered directly to an ambulatory provider's EHR via an HL7 interface.
- Fax—messages can be delivered to physician practices via fax upon request.

DOCS4DOCS uses HL7 interfaces to receive laboratory/transcription/radiology results, discharge summaries, operative notes, EKGs, and other clinical messages from participating data sources. Users can choose which reports are delivered to their inbox—for example, inpatient versus outpatient, preliminary or final, and report forwarding to other physicians involved in the patient's care. Data sources can "over-ride" these options when delivery is dictated by regulation for example.

Data senders, such as hospitals and laboratories, must pay to deliver results to clinicians. DOCS4DOCS offers data delivery at a lower cost than alternatives, providing a value proposition to data senders. As a result, they are invested in the system at a business level. This approach to getting data to users consistently and reliably has driven growth and is the basis of INPC's sustainability planning.

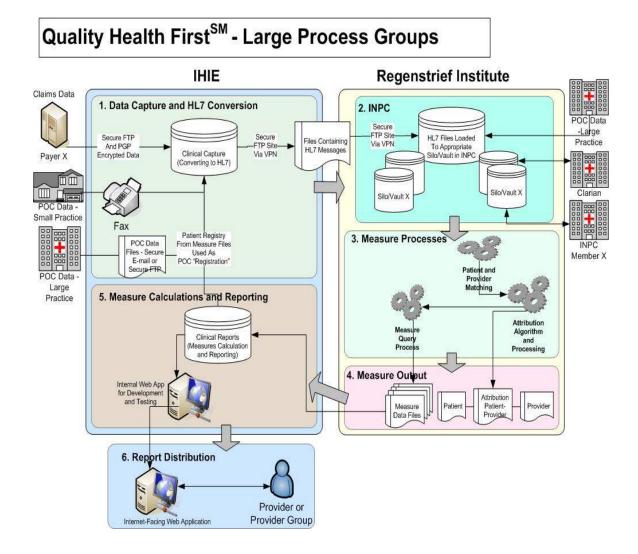
**INPC Clinical Repository and Results Viewer.** The INPC Clinical Repository and Results Viewer is a statewide health repository system that securely aggregates individual patient health information from multiple sources into a single virtual patient medical record, which provides views of a clinical abstract and results of the most accurate, up-to-date information available for a patient, regardless of treatment location. The INPC Clinical Repository is organized by patient and segregated by originating institution. It aggregates data in real-time to ensure current patient information including the following:

- ED visit data (free-text chief complaint)
- Registration records (demographics)
- Radiology reports
- Discharge summaries
- Operative notes
- Pathology reports
- Medication records
- EKG reports
- Laboratory data
- Inpatient and outpatient hospital encounter data demographics
- Coded diagnoses and procedures for hospital admissions and ED visits
- Ambulatory encounter (visit) data.

**Quality Health First (QHF®).** INPC's QHF program was launched in October 2008, to provide patient-level data for two purposes. First, it provides guidance on individual patient's needs, such as whether they are due for a screening test. Second, it provides monthly reports on physician performance quality, using aggregated clinical and claims data.

QHF was developed by physicians, hospital networks, health insurers, the Regenstrief Institute, the Employers' Forum of Indiana, the Indiana State Medical Association, the Indiana Department of Health, and the Indianapolis Medical Society. This program provides physicians with a disease management, preventive care, and reporting service that provides patient-specific and population-based reports, alerts, and reminders based upon needs or incentives of participating providers or payers. This program combines clinical data, medical and drug claims, and point-of-care data to monitor patients' health and wellness (e.g., cholesterol, diabetes, asthma), including Physician Quality Reporting Initiative reporting. Physicians are able to compare their individual results to the physician community as a whole.

There is no charge to physicians and no technology or software required for participation in QHF. Payers provide participating physicians with financial incentives for performance improvement and fund QHF on a patient per month basis. This provides the physicians with information about the care they are providing to their patients and provides payers with data about the quality of care physicians are providing across all patients that a physician cares for.



# Access to Patient Information

INPC uses a global opt-out model that does not require separate patient consent.

# Adoption and Use

As of September 2010, 66 hospitals, two long-term care groups, laboratories, imaging centers, and pharmacies, are connected to INPC. Participation and use has grown and expanded from a focus in Indianapolis and central Indiana to statewide participants. Over 19,000 physicians use the health information exchange. Indiana Medicaid shares administrative data, including prescription records. Surescripts provides medication history for ED patients. Medicare uses INPC data to support pay-for-performance decisions.

INPC is developing connectivity with State and public health departments as both a data receiver and data sender. A total of 78 Indiana EDs are connected to capture real-time chief complaint data for biosurveillance and outbreak detection. The Indiana State Department of Health and the Marion County Health Department share childhood immunization information, public health laboratory results, and tumor registry data. The Indiana University School of Medicine uses the INPC repository data for epidemiologic studies.

### Sustainability Planning

Expanding users and uses allows INPC to distribute costs. Cost distribution supports sustainability. INPC places initial priority on engaging population centers. Some value-added services become less expensive and more technologically feasible as more organizations share the costs of HIE infrastructure. INPC has explored implementing more than 30 value-added services that rely on using normalized data. These include syndromic surveillance, EMT access, and INPC access at mass sporting events (e.g., Indianapolis 500).

INPC has forecasted that it will be cash-positive by 2011. Its operational costs will be covered through its "bundled" subscription fees (including clinical messaging and clinical repository services). Initially, INPC charged per transaction (clinical message delivered). However, large aggregated transaction fees discouraged utilization among large providers and INPC is now transitioning to a membership fee model based upon adjusted patient days.

INPC continually works to identify ways to leverage data, such as electronic lab reporting and surveillance, and determining disability eligibility for the Social Security Administration. INPC continues to study how to measure the actual value of HIE services such as data delivery in the ED and value-added services such as quality measurement. INPC has found changes in care delivery process and management of patients. For example, 7 percent of patients with diabetes are receiving better services for controlling the disease than they were before implementation. However, financial data on medical loss ratio and cost per case data that quantify cost reduction are not yet available. Without aligned incentives, it will be difficult to demonstrate value. Unfortunately for most small practices, there is still no clear financial value proposition for HIE.

INPC maintains that HIE must be viewed as a business that leverages high cost and high value assets. INPC has continually communicated its value to stakeholders to maintain participation and engagement. When health system CIOs expressed concerns that INPC competes with their strategy to create affiliation via IT with ambulatory physicians, IHIE articulated that participation by all hospital systems in the network can help reduce the overall cost of results delivery and communicating with providers. IHIE disseminated to health system Chief Financial Officers the results of a return on investment study that showed initially their costs would not change but that INPC provides the infrastructure for future health care initiatives and cost savings. BioCrossroads' and Regenstrief's initial grant funding for the community helped offset start-up costs for exchange.

#### Next Steps

In March 2010, INPC initiated a study of how to overcome barriers to expanding HIE. Researchers collected survey and structured interview data from INPC participants and nonparticipants, oversampling nonparticipants. Preliminary findings show that many stakeholders are still not well-informed about HIE. Small hospitals report that two major reasons for nonparticipation are financial concerns and lack of IT infrastructure. Several HIE participants were concerned with data confidentiality. INPC is still seeking other data sources (home health, nurse case managers, etc.), as well as seeking to extend services.

# Key Lessons Learned

In addition to the abovementioned staffing skills, INPC/IHIE recommends that emerging HIEs do the following:

- Make community needs their top priority, defer their own goals to community priorities.
- Foster collaboration among all partners and between partners and the communities they serve.
- Realize that HIEs must operate as a business, leverage high-cost and high-value assets, and develop local sustainability (because HIE represents a natural monopoly, HIEs must utilize economies of scale).
- Understand the needs and priorities of potential participants, develop varied value propositions, and develop marketing strategies based on this understanding.
- Ensure that technology developments are responsive to needs of the HIE.

INPC leaders observe that the HIE landscape has changed in many ways over the last 15 years. By the time the AHRQ contract began, INPC had had over a decade to build community trust, assess needs, and respond to issues such as privacy and security. Emerging HIEs will not have the luxury of developing at this pace and must demonstrate value early in the implementation process. The high costs of building infrastructure make it difficult for HIEs to demonstrate their value to stakeholders at inception and delaying value creation can slow the HIE's momentum. Emerging HIE's do, however, have the advantage of existing data nomenclature standards such as LOINC and RxNorm, technical solutions for patient matching, and commercial products for HIE.

# Rhode Island current care Narrative Profile

# September 1, 2010

Targeted Geographic Region: Rhode Island Target Population: 1,000,000 (entire State) Expected "Go-Live" Date: Spring 2011 Projected Data Exchange Volume: Initial go-live is to include 90% of statewide laboratory results and medication history records for 100,000 registered consumers. Progressive expansion will include 1 million registered consumers and their radiology reports, standard medical summary information, vaccinations and other priority data types.

# Initial Planning and Implementation

Rhode Island's SRD Project was a collaborative effort between Rhode Island's Department of Health (HEALTH) and the Rhode Island Quality Institute (RIQI). In 2004, AHRQ awarded the SRD contract to HEALTH. HEALTH was to develop the HIE system through a public-private

collaboration while RIQI provided community governance. A broadly representative steering committee provided detailed project oversight and support for community-driven policy and technical development of the statewide HIE system, known as current*care*. In conjunction with RIQI's existing board of directors, these groups provided a model for developing a long-term governance structure that has continued to evolve to support post-project operation of current*care*. From the project's inception, HEALTH planned for the eventual transfer of technical operations and management of the HIE system to a State-designated HIO. In preparation for this transition, a competitive process was instituted and RIQI was selected to receive the State's designation as the Rhode Island Health Information Organization (HIO). Thus, as the AHRQ SRD Project has been winding down, RIQI has assumed the responsibility for governance, technical operations, management, and long-term sustainability of current*care*. HEALTH continues its support for current*care* in an official regulatory role and as an important partner in statewide HIE planning. Funding for the project and ongoing HIE activities was derived from several sources.

The project's focus and the design of current*care* were intended to advance interoperability among existing health information systems to improve the efficiency and effectiveness of health care in the State of Rhode Island. The project's initial goals were to offer an integrated, patientcentric view of data with the first data types to include laboratory results and medication history. The strategy was to develop a system that would accommodate both clinicians who did not have access to EHRs and those that did, thereby engaging a broad spectrum of health care providers and patients using a range of connectivity options.

### Initial Funding Sources

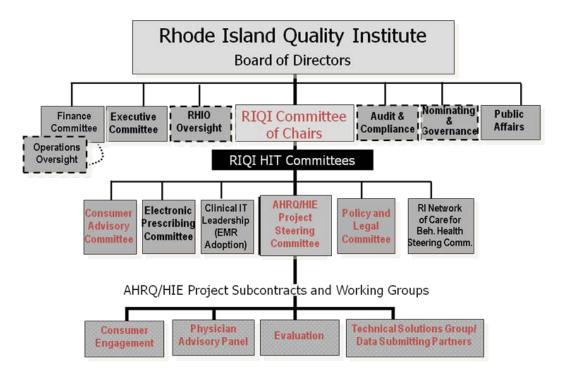
Key funding sources in the earlier stages of current*care*'s development include the AHRQ SRD Project contract, CMS Medicaid Transformation Grant, Caremark Foundation (5 years), congressional appropriation, as well as direct support from RIQI member organizations. Key funding sources for implementation and expansion include State HIE, Regional Extension Center, and Beacon Community Cooperative Agreements with ONC.

# Governance

The structure established for the Rhode Island SRD Project was designed to engage community participants in strategic planning, policy and technical development, testing, training, implementation, and evaluation of current*care*. An AHRQ/HIE Steering Committee was constituted under the leadership of RIQI. Working groups were established to enable productive dialogue with stakeholders offering a broad range of perspectives, concerns, and guidance about the best approach to achieve shared project goals. The Steering Committee leadership facilitated identification of key stakeholders to participate in the project structure and engage in the community process. Over time, active participants also helped determine other potential interested parties and invitations to participate were extended. Steering Committee leadership periodically assessed the composition of voting members to ensure key stakeholder interests were represented. As project scope and priorities evolved, so too evolved the composition of the Steering Committee. For example, as long-term care providers became target enrollment sites and current*care* users, representatives of key stakeholder organizations were recruited to serve on the Steering Committee. Participation on the Steering Committee required committee members to be actively engaged; this included participation in at least 65 percent of scheduled

meetings for any given year to ensure member effectiveness in informing project decisions and advocating for the project.

The figure below depicts the governance structure that was established by RIQI to provide community input and oversight of the AHRQ SRD Project specifically, and development of HIE for the State more broadly. Committees, work groups, and teams listed in red were enacted as a result of, and/or functioned in support of, the AHRQ SRD contract. It should be noted that this structure evolved as HEALTH worked with RIQI to positioned itself to fully operate, manage and govern the statewide expansion of key HIE infrastructure components.



Key support committees for the Rhode Island SRD project included the following groups.

- AHRQ/HIE Project Steering Committee: The Steering Committee served as an integral part of an iterative decisionmaking process that included identifying issues, developing technical solutions and policies, community vetting, and formulating recommendations for Steering Committee consideration, refinement, and approval. The Steering Committee also assisted HEALTH in the approval of various contract deliverables related to the project.
- RIQI Committee of Chairs (CoC): The CoC comprised chairpersons of all committees involved in the HIE initiative. Some of these committees operated across all of RIQI's activities while others were solely focused on HIE project work. The CoC's role was to serve as a coordinating body and a communication vehicle among committees.
- RIQI Consumer Advisory Committee (CAC): The CAC served as a key element of the project's consumer engagement strategy. The group included consumer representation from advocacy organizations as well as unaffiliated consumer participants. The CAC

provided consumer input and feedback on all aspects of RIQI's work, particularly the development, implementation, and operation of the HIE system.

- RIQI Policy and Legal Committee (PLC): The PLC's main role in the SRD Project was to identify, interpret, and create the legal parameters for the HIE system. They also helped guide development of the necessary policies, procedures, and legal safeguards under which the HIE system would operate. The PLC was also charged to address legal and policy matters associated with creating and operating the HIO.
- Technical Solutions Group (TSG): The TSG was an SRD project-specific working group that advised the Steering Committee on technical issues associated with building current*care*. This group developed and presented recommendations to the Steering Committee regarding prioritization of data elements for exchange, identifying data standards, developing HIE functional requirements, proposing technical solutions and acceptance of technical contract deliverables.
- Professional Advisory Panel (PAP): The PAP was an SRD project-specific working group charged with providing physician input into the development and deployment of current*care*. The PAP provided detailed feedback on policies, procedures, and desired system functions and features.
- Evaluation: The project evaluation team was comprised of evaluators contracted through Brown University working under the direction of HEALTH and with guidance from AHRQ.

# Staffing Requirements

When considering requirements to support ongoing operation of a statewide HIE system, RIQI and HEALTH have identified the following staffing capabilities as essential:

- Efficient and effective leaders, directors, and project managers with decisionmaking authority.
- Technical experts who understand the project's goals, objectives, and policies and who can ensure that technical architecture and policies align (this includes at least one technical expert who is employed full-time by the HIE system operator and is invested in its success without competing interests, such as being employed by the technical vendor).
- Staff who effectively engage the public and ensure the project is responsive to community needs and policies.
- Staff who facilitate and maintain provider relations.
- Customer service/consumer relations representatives.
- Physician liaison to facilitate patient enrollment and provider adoption.
- Marketing and public relations experts.
- Legal experts.

# Stakeholder Engagement

Implementing a statewide HIE effort, such as that contemplated for current*care*, requires a consensus-driven approach that relies on engaging a broadly representative group of stakeholders. Identifying and managing differences between community HIE priorities and those of individual organizations is a challenge that must be addressed. Using the committee and working group structure, stakeholders were actively engaged to inform key decisions regarding project direction. For example, current*care* leadership did not pursue a laboratory results delivery model due to business dynamics in the Rhode Island laboratory services market, which is dominated by hospitals and regional laboratories. Instead, Rhode Island stakeholders supported a query-based clinical viewer model that would offer authorized providers access to an integrated view of a patient's high value health information types such as laboratory results, medication history, and a range of reports (e.g., radiology, consultations, surgical reports, and discharge summaries).

For the current*care* initiative, RIQI and HEALTH undertook an intense consensus building effort to ensure that appropriate privacy and confidentiality safeguards were in place. In response to a lengthy community process, Rhode Island passed the RI HIE Act of 2008 to address specific privacy and confidentiality protections as they apply to the statewide HIE system.

As current*care* was being developed, a key issue that impacted some of the developing partnerships was concern that critical stakeholders may identify perceived risks to their own organization's business interests thereby potentially affecting their willingness and/or ability to fully participate in the statewide HIE effort. However, in order to obtain adequate data exchange volume, HIOs may need to engage stakeholders who hold these perceptions. In such cases it may be challenging to present a relevant value proposition that could compel resistant stakeholders to participate. While HIOs often choose to address this issue by including these stakeholders in the decisionmaking process, this approach is not without challenges. Broadly inclusive value propositions tend to emphasize overall savings as a benefit without acknowledging that savings to one party may be lost revenue to another.

The decision by a given stakeholder to participate in a statewide HIE initiative requires balancing business interests and strategic IT direction with the potential benefits and risks of participating in a community-based HIE system. Rhode Island has found that engaging stakeholders requires being able to articulate an in-depth understanding of the potential value and risks of participation in large scale HIE efforts, including how participation can augment stakeholders' roles and responsibilities in the community while preserving competitive interests to the extent required. Development of nuanced and individualized approaches are required to engage a broad range of stakeholders to participate in organized HIE activities.

To accomplish project objectives, HEALTH established contracts for essential components. Key business partnerships in support of current*care* (for some or all of the project period) are listed below.

#### **Contractors and Services**

- PR/Communications/Consumer Engagement: Clarendon Group
- Provider Engagement: Quality Partners of Rhode Island (State QIO)
- Governance: Rhode Island Quality Institute
- Planning and Operations: RI Department of Health August 2004 June 2010, transitioned to RIQI in July 2010
- HIE Technical Infrastructure and Support and Systems Integration: Hewlett Packard (formerly EDS)
- HIE Software (subcontractors to Hewlett Packard)
  - o Clinical Viewer: InterSystems' HealthShare
  - Patient Matching/MPI: QuadraMed
  - Identity Management/User Management: OpenSSO (Sun)
  - Terminology/Mapping: Apelon
- HIE Evaluation: Brown University

# Prioritizing Information to Exchange

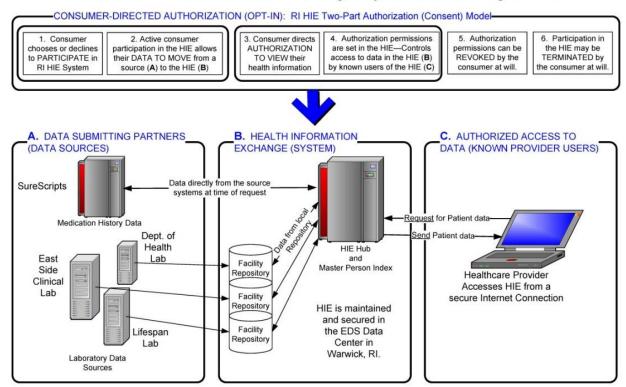
Initially, using a stakeholder-driven process informed by factors such as clinical relevance and technical feasibility, HEALTH prioritized exchange of lab and medication history data through the statewide HIE system. Building the capability to exchange lab and medication history has been challenging for a variety of reasons; however, the project has been able to resolve challenges encountered to support capabilities for the planned exchange of laboratory and medication history data through current*care* in 2010 with radiology reports and patient summary data (via a standard continuity of care document (CCD)) to follow.

Current*care* representatives indicated that the prioritization considerations for HIE in Rhode Island are somewhat different today compared with 5 years ago because of the nationwide push for electronic health record (EHR) adoption and the increased adoption of EHRs within the State (approximately 40 percent). The emergence of EHR aggregator solutions that connect to HIE systems offer alternatives to the proliferation of a large number of point-to-point connections between EHRs and between EHRs and the statewide HIE system. As current*care* leadership positions the statewide HIE system to operate in today's evolving health IT environment, efforts are underway to help support providers' achievement of Stage 1 Meaningful Use criteria via use of EHR aggregators, and the Direct Project. This approach will provide support for exchange of priority information such as laboratory results and medication history records while also supporting clinical summary exchange (CCD).

Current*care* is expected to be implemented in a live production environment by the first quarter of 2011, initially exchanging laboratory results and medication history data between hospital emergency departments, nursing homes, private providers, and community health center partners. Additional data submitting partners will be added to expand the number of participating laboratories and enable the exchange of CCDs. Patient summary reports and other types of health information from EHRs have started to be made available through RIQI's Limited Electronic Health Record Aggregation (LEAP) Project. Initial implementation of LEAP began in June 2010. Integration of EHR aggregators with current*care* is in development.

# System Design and Implementation

Current*care* stakeholders simultaneously developed functional requirements, technical architecture design, and policy. These critical development components were realigned as necessary to ensure the technology solution supported policy decisions. The commercially available software solution that supports current*care* underwent significant customization to enable it to satisfy community-defined consent management requirements. The figure below illustrates the two-part consent model adopted by the Rhode Island community for current*care*. Policy development has been a primary focus since the inception of current*care*. Initially, project leadership developed a list of policies necessary to operate a functioning HIE system. This list was distributed to committees assigned to work on issues relevant to each policy. In



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collaboration with the community groups whose interests they represent, the committees initiated, edited, and refined the policies. The project management staff then reconciled the various versions of the policy, with the Steering Committee serving as a moderating body. The Steering Committee reviewed the final vetted policy statements and related procedures for appropriateness, made recommendations regarding approval, and conducted formal votes to signify full consensus on all approved policies.

RIQI continues to use a similar process for ongoing policy management, review, and development. Policies are periodically updated in response to State and Federal legislation, such as the HITECH Act, constituent priorities, and practical considerations. All policies pertaining to current*care* are subject to State review under regulatory provisions of the RI HIE Act of 2008. Final policies are posted on the current*care* Web site, are open to public comment, and are cyclically reviewed and updated as required.

## Access to Patient Information

The Rhode Island HIE system authorization (consent) model is an example of community priorities shaping currentcare policy, functional requirements and technical architecture. Consumers and other stakeholders provided input and participated in discussions over a 24month period regarding consumer authorization to access information in currentcare. Health care providers indicated that the system should exchange comprehensive health care data, without blocking any specific types of data, in order to preserve clinical relevance and provide value to clinicians. This approach would enable currentcare to include mental health and substance use information and other health data deemed "sensitive" under the law. Legal experts indicated that this approach would require a conservative interpretation of State law regarding disclosure. The resulting policy requires that patients provide authorization at two levels: (1) Participation in the system—affirmative participation by a consumer permits patient-specific health data to be transmitted to current*care* from the originating source and (2) Disclosure to a treating provider several options enable consumers to authorize specific providers to access their health information from the currentcare system. Currentcare maintains a temporary authorization policy which allows treating providers to view patients' medical information in an emergency or unanticipated situation if the patient consented to having their health information in currentcare but did not specifically designate the emergency provider as an authorized provider. Consumer notification is required for temporary authorization to access health information.

# Adoption and Use

Community stakeholders have been actively engaged throughout development and testing of Rhode Island's statewide HIE system thereby establishing a strong precedence for continued participation throughout implementation, adoption and use. Providers have been instrumental in ensuring current*care* usability. Consumer groups including AARP and other health consumer advocates serve on its Consumer Advisory Committee to preserve the consumer voice and ensure proper privacy safeguards. Lawmakers and policy experts have actively contributed to development and refinement of the legal and policy basis for operating the system. In support of continued visibility and outreach, RIQI has developed content for consumers and providers on the current*care* Web site, including fact sheets, videos, and Frequently Asked Questions.

Consumer registration (enrollment) in current*care*, which began in summer 2008, has been a major focus of RIQI's consumer and provider engagement efforts. Since then, RIQI has undertaken several enrollment strategies:

- Direct mailing.
- In Fall 2008, a random sample of 25,000 Medicaid patients were contacted by mail, resulting in the enrollment of 659 patients.
- Targeted enrollment at long-term care facilities.
- Onsite enrollment at community health centers.
- Enrollment as part of hospital outpatient registration.
- Provider-based enrollment.

- Providers receive a \$3 per patient incentive to enroll patients in current*care* that is paid by RIQI and partially funded by a Medicaid Transformation Grant.
- Clinicians inform patients about the HIE and invite them to enroll. This has resulted in a large increase in enrollment.
- Community targeting.
- This strategy included a public awareness campaign, direct mailing, and coordination with community providers in a specific geographic location.
- Enrollment Web site offering an online option for enrollment.

As of August 2010, nearly 82,000 individuals were enrolled in currentcare.

#### Implementing the current care Authorization Model

Rhode Island's HIE Act of 2008 was enacted to establish safeguards and confidentiality protections for current*care*. Its policies are stricter than HIPAA and do not allow access, release, or disclosure of confidential health care information through the HIE system without patient authorization.

The current*care* team found that legal counsel from organizations might interpret privacy and confidentiality provisions differently. A panel of lawyers provided differing perspectives on the required current*care* authorization model relative to their interpretation of the meaning of "disclosure" in State mental health law: some thought the law would not allow data to be viewed (disclosed) without consent; others thought it meant data could not be sent (disclosed) to the HIE system, current*care*, without consent.

Because of this difference in legal interpretations, current*care* stakeholders selected the most conservative model: data cannot be moved to current*care* without patient consent, meaning that no patient data can leave a facility's firewall without patient authorization that allows it to flow to the HIE system. In addition to the conservative approach to first obtain authorization before information is moved to the HIE (first authorization), current*care* also requires explicit consent to enable the release of patient information to providers (second authorization).

Using this approach, patients have some control over who can see their information. However, given the strict protections offered under this two-level authorization model, patients cannot selectively prevent access to certain types of data, such as HIV or mental health information. Providers insisted on an "all" data approach to support informed clinical decisionmaking.

The current*care* team found that vendors do not always have the technical capability to implement the policy decisions made by an HIO. Once the current*care* authorization policy was finalized, the selected HIE vendor had to change the system architecture and pursue additional software development efforts to implement this policy.

#### Sustainability Planning

RIQI engaged Boston Consulting Group (BCG) to prepare a business case and value analysis for RI HIE system. Using conservative estimates, BCG estimated the HIE's value to a range of beneficiaries, and then calculated the funding levels to be expected from each of these groups. While modeling indicated a high overall return on investment, the savings are diffuse and do not accrue equally to all stakeholders. This fact has presented a challenge for developing a clear, broadly accepted value proposition. RIQI developed plans to support HIE system operations and growth through an assessment on insurance claims transactions, similar to a model used by the State of Vermont. However, in the current economic environment, legislative efforts for this initiative were not pursued during the 2010 legislative session. RIQI is continuing its efforts to develop a similar long-term sustainability plan and determine the feasibility of introducing it in the 2011 legislative session.

### Next Steps

RIQI aims ultimately to enroll all Rhode Island patients in current*care*. A near-term priority is to establish the capability to interface EHR data into the HIE system using EHR system aggregation solutions being developed at the community level. Use of EHR aggregators eliminate the need for physicians to toggle between EHR and current*care* views to obtain patient information. Ideally, the aggregator will be interfaced with the HIE system rather than building numerous point-to-point connections with individual EHRs. RIQI's LEAP project is underway to help determine requirements for connecting health centers, specialists, and hospitals via use of EHR aggregation solutions. Efforts are also underway to develop a pilot using the Direct Project as another option for transmitting EHR data to current*care*. The next phase of RIQI's work will focus on expanding the number of discrete types of health data that can be exchanged through current*care*, including connecting EHR aggregators with current*care*. Considering the emerging HIE frontier resulting from extensive Federal investment in accelerating electronic health information exchange goals to achieve meaningful use of technologies in order to realize improved health outcomes.

# Key Lessons Learned

In addition to the abovementioned staffing needs, current*care* had the following recommendations for emerging HIOs and HIE systems:

- Consider and define market dynamics, policies, and user priorities early in the planning process.
- Develop technical and policy infrastructure simultaneously and preserve alignment on an ongoing basis.
- Identify data sources and data sharing partners whose participation will make data exchange useful and of high value.
- Develop a plan for engaging all critical stakeholders that serves to actively address overall project goals and reconcile them with varying business needs which could pose potential challenges to participation.
- Ensure that all technical support details are thoroughly vetted and actively tested, including disaster recovery and business continuity practices.
- Technology has evolved since current*care* was initiated. Emerging HIOs should consider current technology and context (e.g., increased penetration of EHRs, when designing and implementing HIE initiatives).

# Vanderbilt University / Mid-South e-Health Alliance (MSeHA)

# September 1, 2010

Targeted Geographic Region: Memphis region, 3 counties in southwest Tennessee, northern Mississippi
Target Population: approximately 1.3 million residents
"Go-Live" Date: May 23, 2006
Data Exchange Volume:
222 physicians, 131 nurses, and 18 hospitalists
Provider facilities: 15 hospitals and 15 ambulatory clinics

- Provide facilities: 15 hospitals and 15 ambulatory clinics
   Usage: Average of 6.8 percent of all visits in each participant ED
- Provider facilities: 14 emergency departments and 15 ambulatory care clinics.
- Total patients in system: 1.32 million total
- Encounter records: 6 million total
- New laboratory data: Averaging 80,000 lab messages received daily
- New radiology reports: Averaging 1,200 per day
- New discharge summaries: Averaging 150 per day

#### Initial Planning Process

Tennessee Governor Phil Bredesen's advocacy for HIE begin prior to the AHRQ award to Tennessee and to Vanderbilt. In a February 2004 address entitled "Saving TennCare." Governor asked Vanderbilt University to take the lead by working with the Regional Medical Center at Memphis (the MED), a major TennCare provider, to help establish an evidence-based medicine initiative. By late May 2004, the Governor decided that a broader medical informatics initiative involving multiple health care providers and stakeholders, and multiple communities, could benefit not only the TennCare population, but also the broader patient population in the greater Memphis area and the state. In June of 2004, With Accenture, the Vanderbilt Center for Better Health initiated a 6-month HIE planning engagement to study the feasibility of HIE in Memphis and the surrounding region. Concurrent with this planning, Vanderbilt proposed a response to the ARHQ SRD RFP based on its operating technical architecture and its vision for an evolutionary approach to HIE. Policy drove technical development from inception. The Mid-South e-Health Alliance (MSeHA) was formed as a nonprofit organization to be the legally responsible party overseeing HIE in the Memphis region. It was permitted to use technical architecture developed at and operated by Vanderbilt University as a starting point, but expected to transition to a fully independent platform. Vanderbilt created and managed the system for over 3 years of operation. The transition to using a commercial HIE solution offered by Informatics Corporation of America (ICA), based upon Vanderbilt's platform, was completed by July 1, 2010.

#### Initial Funding Sources

MSeHA's funding sources over the past 5 years have included the AHRQ SRD contract and funding from the State of Tennessee. The latter included a legislative appropriation in excess of \$6 million.

## Governance

Tennessee's Commissioner of Finance and Administration assigned the initial governance members based on a governance structure proposed during HIE planning. With extensive input from Memphis stakeholders, he assigned initial members to the board. Decisions were guided by feasibility assessments, a focus on developing and maintaining community trust, and the goal to maximize data exchange volume. The primary focus was to maintain 100 percent involvement of the area's hospitals and to create "quick wins" to maintain exchange.

The MSeHA Board of Directors includes representatives from its data-sharing partners, delivery organizations, and county and State governments. The following key work groups manage Vanderbilt/ MSeHA work.

- The Operations Committee, which developed from the Privacy and Security Group, meets regularly and is responsible for the majority of day-to-day operations of the organization. All participants have the option of participating in Operations Committee activities. HIE professionals, providers, lawyers, and privacy and security personnel are represented on the committee.
- The Financial Work Group addresses topics related to return on investment and developing a sustainable business model. This group meets very infrequently.
- The Technical Group is responsible for implementation at participant sites. This group meets very infrequently now that the exchange has been implemented in most of the hospitals in the target area.

# Staffing Requirements

Vanderbilt identified the following staffing skills as essential to its functioning:

- An active program advocate and liaison
- Expertise in policy
- Political engagement skills
- Expertise in customer relations
- Expertise in privacy policy
- Strong project management and coordination skills
- A highly skilled and integrated software development team
- A senior staff member with understanding of overarching project goals and technical functioning.

These skills remain essential, although many technical issues are now the responsibility of ICSA, the HIE vendor.

# Stakeholder Engagement

MSeHA's stakeholder engagement efforts were focused on addressing the needs of hospitals and their clinicians. Because hospitals are core data sharers and through their emergency departments were most likely to address measurable health care quality and cost concerns, their participation was viewed as the most critical. MSeHA took a conservative approach to engaging non-hospital stakeholders. The board believed that this was the most prudent approach in light of the need to remain focused on the emergency departments and a

#### **Business Partners**

- Tennessee State government
- 30 provider facilities
- Vanderbilt University

#### Collaborating Groups

- Memphis BioWorks Foundation
- QSource (Quality Improvement Organization)
- TennCare
- Tennessee Hospital Association
- Tennessee Healthcare Information Management Association
- Healthy Memphis Common Table
- Memphis Business Group on Health
- Memphis Tomorrow

heated political climate in part due to TennCare reform. Tennessee's Governor and Commissioner for Finance Administration acted as the main conveners of stakeholders in the Memphis region during the initial meetings. The Commissioner and his staff have been regular participants throughout the grant period.

The Vanderbilt Project's initial focus was to collect data from every hospital encounter, with a long-term plan to expand to ambulatory clinic encounters. These data were then to be made available to support care first in emergency departments and later in safety net clinics. MSeHA has developed organizational partnerships with QSource, the Memphis Bioworks Foundation, the Tennessee Hospital Association (THA), and the Tennessee Health Information Management Association (THIMA). QSource, Tennessee's Quality Improvement Organization, collaborates with MSeHA to be the State's Regional Extension Center. The Memphis Bioworks Foundation provides specific support services to MSeHA including housing its ED database, financial oversight, and various administrative services. THA facilitated engagement with MSeHA's hospital partners.

Initial data exchanges were in emergency departments since timed cost was a common concern of all hospitals and of the State. In addition, hospitals were the health care providers most likely to use data. MSeHA's Board of Directors decided that the system's usefulness should be demonstrated in emergency departments before expanding to other settings.

Vanderbilt/MSeHA believes decreasing barriers to participation in the exchange and "quick wins" were critical to its success. Using Vanderbilt servers and software kept technology expenses to a minimum and supported its approach of incremental goal achievement. Vanderbilt estimates expenses during the contract period for IT services at market prices would be at least \$3 million higher.

MSeHA developed a simple and secure Web interface to ease viewing patient data. Separation of data by site, in a federated data model, facilitated stakeholder participation and trust. This allows

MSeHA the operational efficiencies afforded with a centralized exchange and the participant control associated with a decentralized model. If an institution no longer wants to participate in the exchange, all data not used for care transactions can be made unavailable to the HIE (subject to terms of data sharing agreements). Another approach to decreasing barriers was placing minimal reliance on national standards. MSeHA believed that gaining consensus on data standards prior to data exchange was infeasible and would limit initial participation. Rather, Vanderbilt labeled data according to specific descriptors to allow integration. The system retained the original data format so that its data could be transformed at some future date. This approach to data management has been the foundation of Vanderbilt's own information systems for over 15 years.

### Prioritizing Information to Exchange

Vanderbilt/MSeHA sought all available data from all participants as early as they could provide it through secure channels. Vanderbilt/MSeHA restricted initial use the exchange of clinical data to hospital emergency departments. All hospitals began exchanging data in early 2006. The first emergency department began using data in May 2006; the first ambulatory sites went live in late 2007. At the time Vanderbilt/MSeHA initiated data exchange, reducing emergency department spending was a State budget priority. Because data exchange among ambulatory sites was not yet mature, the board believed that hospitals emergency departments were more likely to use data. Based on feedback from clinicians, MSeHA emphasized the exchange of clinical data rather than claims data. Although Vanderbilt/MSeHA established clinical data priorities based on clinician and stakeholder input, Vanderbilt found it far simpler to take all data as the hospital "publisher" could make it available. Specific demographic data was essential to allow for matching of records from disparate sources.

MSeHA has not prioritized pharmacy data since it believes other organizations will provide these services. In later years through an AHRQ Grant Contract Supplement, Vanderbilt developed a "medication history service" that took demographic data, and returned medication histories from Surescripts®. Queries were routed from the Exchange to Regenstrief, then to Surescripts. If a result is returned, MSeHA was charged for the transaction. In an average month, 3 percent of patients have information accessed through MSeHA. A total of 6 percent of these patients had a medication history request. MSeHA users have initiated more than 1,100 medication history requests for 1,000 unique patients since June 2009. Initial results were disappointing because the Surescripts facility had data from PBMs with relatively low coverage in Memphis. The returned data increased dramatically as retail chains joined the Surescripts medication history service.

MSeHA plans to expand participation among hospital-affiliated ambulatory clinics by prioritizing implementation in safety net clinics and large pediatric groups. Because of differences in EHR vendors and incentives, MSeHA has found these implementations to be more challenging than emergency department implementations. This is expected to change with the rapid increases in standardization brought forth by the American Recovery and Reinvestment Act of 2009 (ARRA).

# System Design and Implementation

To maximize data exchange volume and "go live" by their target date, MSeHA decided to maintain simple technical architecture and to accept all available data in all formats. The model was based on 15 years of Vanderbilt's experience and, in actuality, differed only minimally from Vanderbilt's internal data repository systems. This emphasis on simplicity and evolution was crucial for stakeholder buy-in to the system. It decreased barriers to participation and facilitated "quick wins." It also placed minimal reliance on existing national standards. For example, as of September 1, 2010, the system has not yet exchanged data in CCD or CCR form, and requests for CCD or CCR exchange functionality had not been made prior to ARRA. MSeHA believes that by not requiring participants to undergo the costly process of upgrading to meet new standards prior to data-sharing, it decreased barriers to participants, facing their own pressing IT needs, could not make externally-required standards a priority unless they met needs other than the HIE.

Because integration to EHRs was not feasible either because of cost of lack of EHR availability, a separate, stand-alone secure Web interface was designed and implemented. This also led to minimal training and technical support.

MSeHA's technical architecture for data storage is a hybrid between a centralized and decentralized data storage model. Each institution transmits data to MSeHA through a virtual private network. ADT data, other demographic information, and claims data elements are stored in a relational database. Though MSeHA stores these data in a centralized repository, data are separated by institution in logical partitions called "vaults." This delineation gives each institution complete control of its data subject to data sharing agreements. It allows institutions to retain primary data ownership and responsibility for data quality. MSeHA believes separation of data by site was critical to achieving stakeholder buy-in. If an institution no longer wants to participate in the exchange, MSeHA can make those data unavailable. The data are not aggregated; aggregation is transient and is the result of a query. Patient records show data from all contributing sites displayed individually in temporal sequence and the site source is always visible. When a user accesses data all information to recreate the transaction is retained in an audit log. MSeHA did not investigate, develop, or implement a commercial or custom eMPI solution. Instead, MSeHA handles patient identity management by utilizing record matching tables. MSeHA did not consider vendor eMPIs due to both cost and technical considerations. Vanderbilt's systems in Memphis (based on Vanderbilt's approach in its own institution) has performance characteristics equivalent to commercial MPIs.

As of May 23, 2006, all 15 hospital partners began exchanging data. Over time, ambulatory partners contributed data (primarily encounter data but clinical data in one case). Data exchanged were laboratory results, reports, ADT, and allergy data. Discharge summaries were the item most frequently requested and used. Medication history was not exchanged because inpatient medications do not correlate well with outpatient medications. In the last year of the effort, Vanderbilt collaborated with Regenstrief to provide a medication history service.

MSeHA exchange is through two-factor authentication. Users access the system using a SecureID Token that generates a one-time authentication code that changes every 60 seconds. User access is also limited by IP address—users must access the system from a registered

location or MSeHA location. System auditing is performed for each user's access for patients searched, returned records, records viewed, documents viewed, and log-in activities. All updates and inserts are recorded for demographic and clinical data.

In order to accept and exchange data from all participants, Vanderbilt investigators, working with MSeHA's lawyers and stakeholders, established comprehensive data-sharing agreements. Technical staff then wrote parsers for data feeds, using tagging to identify types of data elements and to ensure linkage to patient identifier information. The record locator service was separated from the clinical data and does not store patient data. ADT information was used as the basis for the record locator service; these data were represented in relational database format. Clinical data were kept in a variant of Vanderbilt's StarChart architecture. A team of experienced technicians (usually about five people, though this varied over the course of the contract) parsed data and developed matching algorithms to link data in chronological order. MSeHA viewed matching data as nonscalable due to the resources needed to maintain accurate mapping algorithms. Data providing hospitals are responsible only for confirming data's accuracy. Vanderbilt/MSeHA retains all data in their original formats for archival and review purposes. Laboratory results and panels are mapped to LOINC at the presentation layer to improve display of laboratory data.

MSeHA's affiliation with Vanderbilt University allowed it to leverage technology developed at the Vanderbilt Informatics Center and Department of Biomedical Informatics. Utilizing its servers and software was critical in controlling technology expenses and achieving "quick wins." After this implementation phase, MSeHA has been transitioning to a commercial HIE vendor provided by Informatics Corporation of America (ICA).

### Access to Patient Information

MSeHA maintains an opt-out consent model with notification managed through providers. Although Tennessee law does not require MSeHA to gain consent, MSeHA provides patients with an opt-out option at the institutional level. MSeHA policy requires that all patients be notified of the role of the HIE and their opt-out options. In January 2009, the cumulative opt-out rate was 3 percent.

# Adoption and Use

Vanderbilt/MSeHA supports data exchange among most emergency departments in the region it serves. The board plans to expand to ambulatory care settings. As of March 2009, 15 emergency departments and 15 ambulatory sites had access to the system with over 6 million patient encounters. Users comprised 222 physicians, 131 nurses, and 18 hospitalists. There are over 1.3 million unique individuals with clinical data available through the exchange.

After implementation in most EDs, Vanderbilt/MSeHA focused on expanding ambulatory participation by prioritizing implementation in safety net clinics and large pediatric groups. In the early planning stages, the board set a rule that, in order to use data, an organization needed to contribute data. In April 2009, MSeHA defined a 6- to 12-month plan to add ambulatory users. As ambulatory participation increases, MSeHA will assess its effect on quality and costs. The project reports its most immediate "win" as integration with the County Clinic's NextGen EHR system. In addition to data types provided by most hospitals, medication information was

included because ambulatory medications were felt to be more consistent and accurate than the many transient medications administered during hospitalization.

MSeHA's usage analysis, conducted as part of its Evaluation Plan, has revealed lower—and different—usage than originally predicted. However, an informal survey conducted by the project suggests that these usage numbers may be line with other similar exchanges. MSeHA measures usage at each site at the provider level. It has found that usage patterns differ significantly across sites. At some sites, the nurses primarily access the system—printing out charts for physicians. At another, the physicians access the system during the patient visit.

MSeHA experienced lower usage among EDs than ambulatory sites. Clinics without EHRs had higher utilization rates. Clinicians who would not otherwise be able to access patients' data were more likely to use the MSeHA system. Ambulatory walk-in clinics that used the system increased their efficiency since they no longer had to wait for faxed patient data. Because hospitalists have access to patient information through an EHR, they are less likely to use the MSeHA system unless they need to find information from past hospitalizations that occurred elsewhere.

#### **MSeHA Policies and Procedures Development**

MSeHA relied on the Markle Foundation's *Connecting for Health* framework in its policy development process. Dr. Mark Frisse was a co-chair of the group developing the Markle policies and was permitted to use drafts in the preparation of the Memphis documents. *Connecting for Health* was critical in formalizing MSeHA's framework for data-sharing agreements; variants of the MSeHA's agreements have been used by organizations in more than 30 States. The 9-month policy development process was as challenging and as important to the HIO's success as technological development (and policy refinements are ongoing). MSeHA found that a model contract specifically assists with identifying most of the issues that an HIO needs to discuss and achieve consensus. It does not provide the answers, but poses the questions that HIO participants need to answer.

MSeHA wrote policies regarding patients' rights, privacy, and access management prior to the system being used. Indeed, because of concerns over consent, hospital data prior to the May 2006 start was flushed from the system so that no data were available prior to a date in which data requests were made and consent was obtained. MSeHA also developed reporting and auditing procedures to assess the use and accuracy of data exchanged. They also developed forms and policies relating to the following areas.

#### Participant and Registration Policies

- Participant Agreement
- Registration Policy (contains form of Registration Application/Agreement)

#### Enrollment Forms and Policies

- Alliance Confidentiality Statement and Policy
- SecureID Token Request Form
- Terms of Use Form for SecureID Token
- User Set Up Information Chart

Over the course of developing policies and procedures, MSeHA educated participating organizations' legal counsels.

#### Governance Policies

- Policy on Policies and Procedures
- Policy on Coordination of Alliance Policies and Participants' Policies
- Privacy and Security Policy
- Conditions to be Met before a New Data Provider's Data May Be Used
- Roles and Responsibilities
- User Access
- Auditing and Reporting
- Mitigation
- Insurance Policy

To address legal concerns, MSeHA developed several agreements for participation in the exchange. Among these were participation agreements, registration applications and agreements, and enrollment forms. These agreements allowed MSeHA to make the policies and legal concerns of the exchange clear to participants. MSeHA initially allowed data use for only diagnosis and treatment, then expanded to include coordination of care. Strict data use agreements supported developing trust among stakeholders.

MSeHA indicates that it is important to remember that the Model Contract provides a framework for a common approach, identifying areas that need to be addressed in agreements. MSeHA kept most of the construct from the Model Contract and made a few deliberate changes, which should be expected. Using the Model Contract and Model Policies enhanced MSeHA's engagement with legal counsel later in the process by providing a baseline framework and example language. After implementation at the first site, MSeHA revisited the framework and made changes to policies to reflect the desired language and intention.

### Sustainability Planning

MSeHA's sustainability plan is based around its minimalist system, which is designed to create value at low cost to stakeholders. If costs are low, the need for financial returns is not high. Over the long-term, stakeholders are expected to pay in proportion to the benefits they receive from the exchange. MSeHA, in collaboration with the Tennessee Hospital Association, developed a model that estimated the value conferred to each stakeholder by assessing various characteristics of the participants including size, number of admissions, and net revenues. This formula assumed benefits were proportional to size and volume and added a progressive fee based on revenues so that hospitals in financial peril could participate.

Participating hospitals have had free access to Vanderbilt/MSeHA since joining, but have invested significant effort in implementing the system. As a result, these partners were reluctant to begin paying participation fees. In addition, payers who contribute to the exchange expect full access to their patients' data. Partitioning the data to allow payers to see only their insured population's data presents a technical challenge. MSeHA's experience suggests participating hospitals should be financially invested in the exchange from the outset.

MSeHA has determined that it is important to clearly communicate the business case for participating in the exchange. Development and operational costs since inception in 2004 have totaled approximately \$10 million. Total annual costs for the exchange are \$1-1.5 million, or no more than \$1.50 per individual per year. The Memphis region has a population of approximately 1.3 million. MSeHA has found that the total cost is best communicated to stakeholders as \$1 per citizen, per year. Indirect costs associated with time and effort of participating in the exchange (e.g., hospital IT time, data quality checks, executive participation) were estimated to be approximately \$50,000 for hospitals and less for ambulatory care providers.

MSeHA has estimated costs associated with future development and expansion. It has estimated the following one-time costs (with annual operational costs at about 10 percent). These estimates are considered unreliable and probably high.

- Connecting with a vendor that has interfaced with the exchange: \$46,000
- Connecting with a new vendor: \$80,000
- Public health—reportable conditions: \$50,000
- Public health—populations and surveillance (basic): \$50,000
- PHR interface: \$50,000.

While MSeHA has shown that the exchange decreases costs through the reduction in duplication of tests and services and that these savings do not generate sufficient revenue to sustain the exchange, this is more the result of low Exchange costs than measurable savings in emergency departments. MSeHA predicts that increased participation and coordination will further reduce costs enough to make the HIE sustainable. Although ambulatory connectivity costs will be high the benefits accrued through more accurate quality measures and care coordination are believe to exceed the costs by a significant degree.

MSeHA attributes its rapid success to its architectural structure—the key to success is responding to community needs without being unnecessarily complex or expensive. The aspects that made success possible were annual indirect employee costs (e.g., time, labor) of less than \$50,000 per hospital; a total annual cost of \$1.50 per patient; matching rather than mapping data; and minimal reliance on common standards.

#### Next Steps

MSeHA has shifted its focus from ED implementation to transitions in care, while completing initial rollouts in ambulatory facilities. The board is discussing approaches for engaging long-term care facilities, specialty providers, and free-standing radiology/imaging centers.

MSeHA is evaluating how the HIE affects chronic disease treatment; service use and patterns; and test and service duplication, with emphasis on reducing high-priority tests and inpatient admissions. A University of Tennessee group is using claims data to evaluate MSeHA's effects on specific conditions such as back pain, chest pain, and abdominal pain. MSeHA plans to expand analysis of usage patterns (e.g., which parts of the system are being used, and how this differs between ED and primary care physicians).

#### Key Lessons Learned

In addition to the abovementioned staffing skills, MSeHA recommends the following to emerging HIEs.

- Make developing community trust the most important priority; be an integral part of the community they serve, with detailed understanding of community needs, priorities, and politics. At times, MSeHA found itself limited by geographic distance from key stakeholders; at other times, this distance allowed important neutrality.
- Ensure that a "guiding coalition" is present to encourage participation. MSeHA and Vanderbilt were fortunate to have the "hands on" participation of both the Governor and Commissioner of Finance and Administration. Reduce the policy development burden by leveraging model policies developed by MSeHA and other early adopters—such as the Markle Foundation's *Connecting for Health*. Although MSeHA spent much of its first 2 years developing trust and codifying trust through formal HIE governance policies. Participants believe that emerging HIEs will not need to replicate all of this effort, but every group must ponder the issues and both understand and advocate for them.
- Understand that some aspects of an existing HIE's technical architecture may be adopted by emerging HIEs; some will not. Many emerging HIEs will replicate a simple, low-cost technical architecture. However, as EHR adoption increases, HIEs are less likely to be expected to have a centralized data repository and more likely, the "E" in "HIE" will be a verb rather than a noun. NHIN Direct is an example of the growing interest in noncentralized exchange.
- Stay focused on "quick wins" and a "version 1.0" approach that allows standards and practices to evolve.
- Develop concrete and feasible plans for achieving specific goals on schedule.

- Define clear priorities and scope for implementation in order to maintain focus and not allow competing goals to disrupt the project.
- Define sustainability in terms of how long ideas are likely to be valuable, since markets and technology change rapidly.
- Consider how technology and the market are likely to be 5 years from the initial plan. Understand that the principles and approaches should be sustainable but the implementation and organizational approach used to achieve these aims may evolve over time.
- Conduct additional research in determining optimal HIE usage rates and subsequent measureable impact in different care settings. MSeHA recommends determining how data sharing affects morbidity and mortality to address this question. Optimal usage rates may vary by types of service used and care setting.
- Conduct further research on defining test redundancy—that is, when a test could be considered duplicative—and improved methods for monitoring and measuring transitions in care. This is part of a much larger effort that is required to understand the true value of data made available through exchange.
- Build trust among stakeholders at the regional level—particularly between providers and patients. Coordinated statewide efforts face challenges in maintaining this trust.
- Involve local public health departments, as there may be many local initiatives that HIE should be involved with. It is important to coordinate with as many parts of the community as possible.
- Recognize that engaging and coordinating stakeholders presents more challenges than technical development issues.

# Utah Health Information Network (UHIN) Narrative Profile

# September 1, 2010

Targeted Geographic Region: Utah Target Population: 2,784,572 (entire State) cHIE "Go–Live" Date: July 2009 cHIE Data Exchange Volume: 2010 monthly volume average 32,000 messages

### Initial Planning Process

UHIN was formed in 1993 with the goal of exchanging both administrative and clinical data. In 1993, UHIN began convening 14 entities to set administrative data exchange standards and begin the process of exchanging claims information. The AHRQ contract was a catalyst for expanding from exchanging administrative data only to also exchanging clinical data. UHIN maintained its existing governance structure to support this transition. A total of 150 partners, including

medical insurance companies, clinicians, billing services, long-term care providers, and ambulatory care providers, began to exchange claims-related data in 1994.

To transition to clinical data exchange, UHIN updated the UHIN Gateway to allow for administrative and clinical data to be routed. They also updated the UHIN baseline tool to allow for administrative and clinical data exchange. UHIN began creating community-defined clinical standards and specifications in 2004. In 2009, UHIN purchased an additional clinical platform and a clinician EHR tool (e-lite) from Axolotl to facilitate clinical exchange. The Clinical Exchange Committee identified which message types to focus on and how to pilot test providerto-provider message exchange. At this time, UHIN modified its governance to support a more unified approach for administrative and clinical exchanges. Originally, UHIN had separate administrative and clinical data standards committees. Approximately 2 years after the current contract began, participating organizations informed UHIN that meetings were taking too much of their staff's time. In response to this feedback, UHIN staff streamlined the standards (implementation guidance) process to address administrative and clinical data in a single forum.

The provider-to-provider message exchange pilot test began in August 2006. UHIN tested the enhanced baseline tool, which was also used to exchange administrative transaction data. Pilot test results indicated that this tool, which allowed clinicians and payers to exchange clinical attachments (e.g., PDF documents), was not sophisticated enough for clinicians. Clinicians wanted "push" model report delivery and point-of care "pull" model functionality. UHIN responded with issuing a Clinical Health Information Exchange (cHIE) Request for Proposal (RFP) in January 2008. The cHIE system which includes a clinical exchange platform and clinician baseline tool (e-lite) was purchased in January 2009. The cHIE implementation began in July 2009. UHIN researched existing "push" and "pull" model clinical exchanges to assess implementation feasibility. The findings of this research found that "pull" models relied heavily on grants and contracts for their operations. UHIN decided that the "pull" model should be implemented in the future and not be the basis to support its long-term plan for sustainability.

Since inception, a central focus of UHIN's work has been to standardize transactions. One of UHIN's central principles is that standardization facilitates data exchange. UHIN has been working with the Utah health care community to develop clinical information standards for the past 5 years. UHIN is the State convener for standards creation and develops administrative transaction standards for the Utah Insurance Department and clinical message standards for the Utah Department of Health, based on input from the community. Where possible, UHIN tries to adopt national standards. In some instances, the community determines that national standards need to be further constrained. In others, national standards that would address the needs of the community do not exist. The standards development process is open to any interested health care entity.

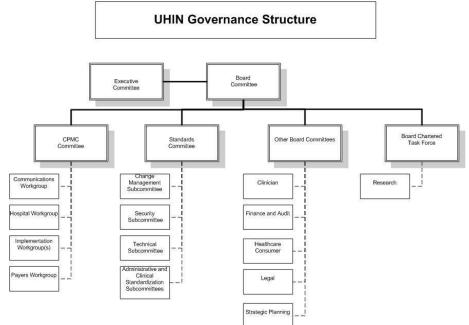
#### Initial Funding Source

In addition to the AHRQ SRD contract, UHIN receives funding from other sources including the Utah Department of Health, and administrative user fees.

#### Governance

UHIN develops relationships with data sharing partners through informal professional networks; formal contacts made based on board recommendations; and by including partners on UHIN's Board of Directors, and UHIN committees and working groups. Membership allows partners to have influence on UHIN's decisions and strategic direction. Stakeholders represented on the board include data sharing partners, technical experts, legal experts, and consumer interest representatives.

The UHIN Board of Directors and committees are the primary mechanisms to support UHIN operations, decisions, and planning. The Board meets quarterly to discuss strategy, key decisions, and to hear executive-level reports on operations. For example, the board made the decision to move to a new clinical system, based on the feedback from pilot sites



that exchanged direct messages using enhanced existing tools.

- The Executive Committee, which has some members who are also on the Board, makes decisions regarding daily operations and recommendations for UHIN's direction. For example, the Executive Committee recommended that UHIN develop policies for consent and assigned specific committees to create recommendations that would be presented to the UHIN Board.
- The Standards, Clinician, Community Program Management Committee (CPMC), and Health Care Consumer Committees are critical decisionmaking groups. Standards and CPMC meets monthly. Other groups meet on an ad hoc basis to discuss issues relevant to UHIN, make recommendations to the board, and receive feedback from the board. The Standards Committee is open to public input.
- UHIN staff identify potential committee chairs and appoint them.
- UHIN Board members and staff also invite community members with an interest in UHIN work to participate in committee work.
- The Health Care Consumer Committees are responsible for addressing privacy concerns.
- The Legal Committee is responsible for UHIN agreements and legal policy.
- The Technical Committee has been in existence for approximately 15 years. Its role is to make detailed technical recommendations on how to operate the network.

- The Technical Subcommittee has provided input regarding all of the data exchange protocol standards that are used by UHIN.
- The Security Subcommittee has created all of the security standards by which UHIN operates.
- The Clinician Committee is responsible for leading provider engagement efforts. Currently, the Clinician Committee is focusing on publicizing the cHIE to physicians. These efforts have been coordinated with implementation efforts through conducting provider fairs and collaboration with the Utah Medical Association and the Utah Hospitals and Health Systems Association. The Committee seeks input from providers to optimize system design and prioritize data.

In addition to committees, work groups form to manage implementation of larger projects, such as the cHIE. These groups are responsible for developing project plans and monitoring progress. Over the course of the project, UHIN has streamlined its processes by merging committees with overlapping responsibilities (e.g., administrative and clinical standards) to help minimize the number of scheduled meetings. The Board and committees are two mechanisms for receiving community input and investment. UHIN also relies on other professional connections and informal networks to ensure it is informed about community concerns and priorities.

## Staffing Requirements

UHIN identifies the following staffing responsibilities as critical to its functioning:

- Committees/workgroups that include community information technology and business experts.
- Project managers and teams with implementation expertise.
- Data quality assurance experts.
- Customer service staff.
- Accounting and human resources staff.

### Stakeholder Engagement

Utah's population is geographically diffuse, with the majority of the State's population on the Wabash front, from Provo to Ogden. Utah contains one large health system, Intermountain Healthcare, which operates 20 hospitals and 160 health care facilities. Utah also has a branch of Hospital Corporation America (HCA), Mountain Star Healthcare, which operates six Utah hospitals. Utah also has a branch of IASIS Healthcare, which operates four Utah hospitals. A regional reference lab, Pathology Associates Medical Laboratory (PAML), is a Mountain Star partner. Planning and implementing of a statewide HIE over a large geographic area has been and remains a significant challenge. UHIN's member organizations have been supportive because they see the potential value of a statewide HIE. In addition, stakeholders' desire to remain competitive in the market, governmental pressure, and economics have encouraged stakeholder engagement. Community involvement in planning and implementation has been essential to UHIN's success. Prior to receiving the SRD contract, UHIN had existing connectivity and relationships with the vast majority of Utah providers for administrative

(billing) data exchange. Currently, UHINet serves more than 90 percent of medical providers in Utah for administrative (billing) data exchange.

Developing clinical standards is a current focus for UHIN. This includes addressing concerns about pull models, and consent and disclosure. There are several emerging concerns.

- The first is a new and growing concept that patients should control 100 percent of any information exchange. There are unresolved complex technical, legal, and ethical issues in this area, including potential conflicts with using the cHIE for public health reporting efforts.
- Some parties, especially one large integrated delivery network, are concerned that the cHIE will result in a significant increase in breaches and in subsequent lawsuits.
- There are also concerns that certain uses of the cHIE may not be covered under HIPAA. The community is actively working to create legal protections for data sources to assuage these concerns.

UHIN is addressing these concerns by convening many community meetings to work toward resolving these questions. UHIN researches available information and presents it at the meetings. This has been limited, but does include examples of legislation from other States and summaries of how other successful HIEs have addressed these issues. UHIN is confident the community will resolve communities' concerns about privacy.

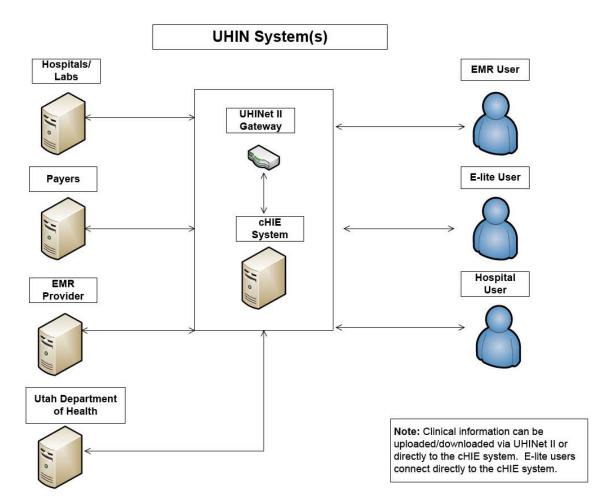
On May 10, 2010, UHIN hosted the cHIE Promontory Point Kick-Off event. The Governor signed a declaration, celebrating May 10, 2010 as Utah Healthcare Connectivity Day, 141 years from the day of historic joining of the transcontinental railroads linking the American people from the Atlantic to the Pacific oceans at Promontory Point, UT.

## Prioritizing Information to Exchange

Decisions regarding prioritizing data to exchange were based on which data were available to exchange. These initially included laboratory results, discharge summaries, medical history, history and physical reports, operative reports, and admit/discharge/transfer (ADT) messages. The Utah Department of Health is in the process of providing immunization and medication history information to the cHIE. After purchase of the Axolotl system, UHIN planned for medication history to be implemented as part of the "query" functionality.

### System Design and Implementation

The following figure illustrates UHIN's technical architecture.



UHIN's technical architecture changed with the implementation of clinical data exchange. The existing infrastructure supported uploading and downloading, but not data storage. Also, administrative data are exchanged between providers and payers. UHIN expanded infrastructure to support report delivery (push model) and point-of-care (pull model) exchange across the community.

UHIN's original plan involved modifying UHINet, its existing administrative data exchange, to create a single exchange for administrative and clinical data. UHINet II was formed as a Web service to exchange all types of administrative and clinical data from the data sender organizations ("payload independent" Web service). It intended to support a range of

#### **Business Partners**

- Clinical System Vendors: Axolotl, RelayHealth
- Hardware and Software: DirectPointe
- Software Development and Maintenance: Axolotl, RelayHealth
- Physician Credentialing to use UHIN: AllHealth

HL7 and National Council for Prescription Drug Program (NCPDP) messages with specifications to be determined by the data senders in the community as a push model. When

UHIN's Board of Directors conceived this plan in early 2005, they accepted the risks associated with this approach because the board believed that this would facilitate UHIN's clinical data exchange capacity and lay the foundation for its future query model.

Based on feedback from the UHINt pilot for clinical data exchange, the community determined in October 2008 that a more comprehensive solution for clinical health information exchange was necessary. In 2009 UHIN contracted with Axolotl Corporation, a provider of health information exchange (HIE) services, to provide the technical infrastructure for the Clinical Health Information Exchange (cHIE). The first phase of cHIE implementation focuses on data sources sending data to the cHIE. This will facilitate the "push" or report delivery of laboratory results, discharge summary, and history and physicals (clinical messaging).

UHIN uses Axolotl's Patient Identifier Cross-Reference (PIX) and Patient Demographic Query (PDQ) as the basis of its eMPI and to perform patient authentication. The PIX and PDQ query the eMPI to retrieve the "community-assigned eMPI number" and patient demographic information, respectively.

UHIN conducted research to verify if community organizations had the capability to create HL7 version 3.0 PIX/PDQ messages. UHIN has been involved with discussions to create a statewide eMPI. Although the future of this initiative is uncertain, UHIN is moving forward with the development of its own eMPI. If required, UHIN's eMPI can be integrated into a statewide eMPI.

Because of Utah's high EHR penetration (about 30-50 percent), UHIN has engaged EHR vendors to interface with UHINet. Despite using UHIN standards, EHR vendors are seeking between thousands and tens of thousands of dollars to create these connections and clinical interfaces.

#### Access to Patient Information

HIPAA regulations form the foundation of UHIN's consent policy. UHIN maintains a hybrid opt-out and no consent model for patient consent. Patients may opt out of UHIN's query functionality though not the results delivery functionality. In addition, for query functionality, providers are required to attest each time they access a patient's data.

#### Adoption and Use

As of May 22, 2010, one lab, two hospitals, and six other data sharing partners exchange lab results on UHIN's cHIE system. Over 1,700 data sharing partners exchange claims data via UHIN's UHINet II Gateway.

To encourage adoption and utilization, UHIN has assessed value propositions for its payers and providers. Because of Utah's high EHR penetration, UHIN has engaged EHR vendors to interface with the cHIE.

• Payers want an HIE to reduce costs associated with paperwork and manual data handling; reductions in duplicate tests, written prescriptions, and emergency department costs; increased member satisfaction; and reduced costs associated with retrieving clinical

information such as Healthcare Effectiveness Data and Information Set (HEDIS) quality reporting and workmen's compensation administration. In addition, payers expect at some point to have access to their members' information via the cHIE.

- Hospitals want HIE to provide high-quality identity management, cost-effective document and message exchange, and medication history data.
- Overall, physicians want HIE adoption to be affordable and integrate smoothly into workflow. Features most demanded by physicians are standardized clinical messaging and EHR integration.

### Sustainability Planning

UHIN's strategic direction and decisions have primarily been driven by its responsibility to develop standards. As UHIN transitioned to clinical data exchange, UHIN Board members ensured that technical and business community representatives were involved throughout the process. Involving this many people and organizations may have slowed the process, but made the review more thorough and increased community investment in community exchange efforts facilitated by UHIN.

The UHIN community set the following benchmarks:

- 1. Reduce number of prescriptions annually
- 2. Increase formulary compliance by 3 percent annually
- 3. Increase use of generics by 9 percent annually
- 4. Reduce ED services/visits by 30 percent
- 5. Reduce ED hospital admissions by 15 percent annually

The UHIN Finance Committee has developed a pricing structure to be implemented in 2010. The proposed pricing for payers is \$0.085 per member per month with a 250,000 member cap or a maximum of \$0.21 per 837 with a \$250,000 maximum. Hospital fees are based on the previous year's discharges with a \$60,000 annual maximum. The committee also proposed an annual membership fee for physicians based on the number of physicians in an office.

#### Next Steps

UHIN is working to initiate cHIE implementation among large organizations, with data to exchange, and in rural areas. The current emphasis is to include every potential data source in the exchange. Implementation is most successful when it minimally disrupts clinician workflow. As a result, UHIN is working with many EHR systems to interface their systems with the cHIE. UHIN is also working with clinicians who do not have an EHR system and may be good candidates for the e-lite system. This involves an assessment to their clinician workflow and how it may be impacted in using e-lite.

UHIN plans to expand to a point-of-care ("pull") model when there is enough data available within the cHIE. UHIN determined that while point-of-care may improve the quality of care, its value is difficult to quantify. Costs and associated savings of report delivery are easier to quantify, making this a sustainable model at this time. UHIN is working with many significant cHIE data contributors to make the point-of-care model functionality available to cHIE users.

## Key Lessons Learned

In addition to meeting the abovementioned staffing requirements, UHIN makes the following recommendations to emerging HIEs:

- Develop a private/public community partnership based on consensus.
- Identify and involve community leadership that understands the importance of doing what is right for the community, not just what may be right for a particular organization.
- Actively involve the community and medical association representatives in sharing concerns and developing approaches in addressing those concerns.
- Recognize that technical solutions are relatively easy compared with understanding and aligning various organizational business strategies with the HIE.
- Emphasize sustainability when determining which data to exchange.

# Conclusions

The variations between the six HIOs reflect variations in the needs of their communities and the HIOs' common response of developing systems to address those needs. In the process of developing and implementing these diverse systems, these HIOs changed the HIE landscape and learned several key lessons about success. Their experiences can inform emerging and ongoing HIE efforts. Their remaining questions can guide next steps in HIE research.

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