
Evolution of State Health Information Exchange/ A Study of Vision, Strategy, and Progress

The Agency for Healthcare Research and Quality (AHRQ)

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Executive Summary

Driven by the opportunities to improve health care quality and reduce health care spending, many Federal, State, and private entities are aggressively pursuing initiatives to improve the flow of clinical, financial, and administrative data within the U.S. health care system. Clinicians would benefit from more timely and accurate information about patients' health status, health history, and "best treatment" information. Patients would benefit from improved access to timely and accurate clinical information and health benefit claims. Public and private payers would benefit from faster and easier access to information on treatment trends and patients' outcomes.

As a result of these overlapping benefits, numerous initiatives to speed the exchange of automated health information are under way at the Federal, State, and local levels. To date, State government involvement in health information exchange (HIE) activities has not received the same attention as Federally-sponsored and industry-sponsored HIE activities. However, State involvement in data exchange activities is growing as States seek a localized HIE-based response to improving health care quality, efficiency, and savings. This report addresses the current State HIE environment and analyzes State-specific HIE activities and initiatives.

The Agency for Healthcare Research and Quality (AHRQ) commissioned Avalere Health (Avalere) to prepare this report to capture and characterize the broad landscape of State HIE activities with an emphasis on identifying trends and best practices in the areas of project financing, programmatic sustainability and patterns of successes, and challenges. AHRQ was particularly interested in those HIE projects in which the State's government, including the Medicaid agency, is actively engaged. To provide the raw data for the analysis, Avalere conducted a general scan of State-based HIE activities and an in-depth review of one State-based HIE project in each of the following States: Arizona, Florida, Hawaii, New York, North Carolina, Rhode Island, Tennessee, and Utah.

States occupy several roles in the health care system: they operate as sponsors of health insurance for their employees; they frequently employ providers to deliver care to their citizens; they regulate the provision of care and insurance; and they provide essential public health services and oversight activities. Driven in large measure by these various roles, the nature of States' projects reviewed in this report varied significantly. Despite this variation, Avalere's analysis yielded a number of significant findings regarding various projects' goals and designs, their levels of progress, and their unique future challenges as they proceed with HIE implementation:

No two HIE projects are alike: Most projects share similar goals to improve quality health care and reduce costs. Beyond these goals, the projects vary tremendously with respect to engaged stakeholders, available funding, community history, selected technology, and implementation strategy. This variation is particularly true for the infrastructure components selected to enable information sharing.

Most projects are still in the early stages: The majority of projects are either in the planning phases or in the early implementation phase, exchanging only narrow sets of data. Publicly available characterizations of projects often indicate greater progress than what proves to be true with further research.

Size and experience affords unique alternatives: States with several years of HIE experience more readily foster broad stakeholder buy-in, while small States may be in a better position to promote a single vendor solution.

Funding varies widely: Federal and State grants are the most common sources of funding. The type and amount of funding varied significantly for each individual project.

Sustainability is the long-term but still elusive goal: Sustainability and a long-term revenue model are primary goals for most HIE projects. None of the projects included in the in-depth analysis have achieved a sustainable funding or operations model. Funding, particularly for infrastructure, will continue to pose a

significant challenge to the longevity and stability of State-based HIE projects. New public and private funding solutions will need to be identified and evaluated.

States are critical stakeholders but their primary leadership role may be time limited: The State plays many critical roles as a funder, data resource and partner, project facilitator, and neutral convener in promoting HIE projects. Many projects currently led by States anticipate turning over the primary leadership to non-profit organizations, due in part to the need for self-sustainability.

Despite the highlighted projects' diversity, certain criteria emerged as keys to success in both the planning and implementation phases, including:

- Strong State leadership and political support;
- Broad stakeholder involvement and early engagement of physicians; and
- Short-term “wins” to demonstrate the HIE value proposition.

For State-based HIE activities to succeed, it will be important for Federal and State decisionmakers to exercise sustained and consistent leadership. The critical goals of such leadership should include the promotion of cross-fertilization of projects, of shared learning, and translating programmatic successes across communities, States, and regions. Federal and State leaders will face the natural barriers and challenges to timely adoption of various HIE projects including bureaucratic inertia, financing, and coordination of disparate yet well-meaning individual HIE activities.

The Federal government has set an aggressive pace for HIE adoption, with the goal of nationwide interoperable electronic medical records by 2014. However, the study highlights that State and local communities are still working to determine how best to engage stakeholders effectively and will be challenged to meet such an aggressive implementation timeline. As Federal and State decisionmakers seek to support the growing number of State and community efforts, it will be important that they bridge the emerging gaps between Federal goals and the realities of local implementation.

With the breadth of activity, the variability of projects, and the fast-paced push from the Federal government, it is clear that the entire health care community – national, State, *and* local – will need to continue to work collaboratively to develop consistent and common mechanisms to interpret, capture, and share the lessons learned about this emerging market and its impact on health care.

Introduction

Background

Community and regional initiatives seeking the value resulting from automated health information exchange (HIE) are emerging more rapidly than ever before. The surge in activity is a result of a number of new and mounting trends including: rising health care costs; inefficient medical care; the delivery of variable and oftentimes inadequate quality of care; and Federal emphasis on and support of interoperable health information technology (HIT) and HIE.

At the Federal level, Congressional and Administration efforts to promote broader HIE adoption and to set national interoperability standards have accelerated activity in this space. State involvement in these activities is also expanding as States respond to these trends and embrace HIT as tools to manage and enable better quality health care. Local health care communities recognize that implementation of their HIE projects is where the rubber hits the road. Against these three streams of activity, Federally established policies, standards, and incentives will only be viable if they are informed by the emerging set of real-world local implementation experiences.

Throughout this report, the authors use two distinct terms: HIE and HIT. The reason for this distinction is that the value and power of automation is in the ability to exchange real-time health information (HIE) when and where it is needed while the technology (HIT) is what enables the information exchange. References to HIT do not always convey the intent of a project or the extent to which available information will be captured and used, where HIE terminology conveys the purpose of the exchange and the supporting technology. The term HIT is only used to refer to technology or in instances where a program or organization uses the term to characterize their activities.

Project Purpose and Description

The Agency for Healthcare Research and Quality (AHRQ) is interested in better understanding current State HIE activity and how AHRQ can facilitate State-based projects, can assist in fostering communication on what States are doing, and can further promote HIE at the State, regional, and local levels.

In summer 2005, Avalere Health (Avalere) was contracted by AHRQ to examine the broad spectrum of State-based HIE activities including projects inside the States' Medicaid programs. Avalere examined State projects working to integrate new and significant HIE activities to improve patient safety and quality, reduce costs, and create greater efficiencies in their Medicaid and/or State health programs. Avalere conducted the study in two phases. Avalere first performed an environmental scan of HIE activity, and then selected a cross section of activities for further analysis. Avalere examined in detail a subset of eight State-based HIE projects to highlight the diverse nature of HIE project designs, the varying degrees of progress, and the unique challenges faced by States as they proceed with HIE implementation. The eight projects are presented in the Case Study section of this report. A full description of the report's research methodology is included in Appendix A.

HIE Environmental Scan

Recent health industry reports and growing coverage of HIE activities highlight the rising interest in the breadth of HIE progress and lessons learned. Many interested communities and stakeholders are either contemplating their own HIT purchases or are wanting to participate in others' formative HIE activities. These reports, in addition to the growing lists of HIE projects available on Federal and private sector Web sites, provide a rough representation of the U.S. HIE landscape, but none of these summaries tend to focus primarily on the role of States in promoting HIT adoption or HIE.

In conducting the environmental scan for this project, Avalere performed literature reviews, extensive web-based research, and examined online resources and several recently published reports¹ with aggregated

¹ Center for Health Transformation (CHT) and IDX report; American Health Information Management Association (AHIMA), Association of Medical Directors of Information Systems (ADIMS), and Healthcare Informatics Regional Health Information Organization (RHIO) Survey; Foundation for eHealth Initiative Second Annual Survey of State, Regional, and Community-Based HIE Initiatives and Organization

information on nationwide HIE projects. Much of the available information relies on self-reported survey data without external validation, represents information at a single – often outdated – point in time, often represents projections or goals as opposed to actual status, and is varied in the level and type of detail provided. These attributes impose obvious limitations to the research and analysis conducted for this report.

As part of the scan, Avalere reviewed a wide array of information on HIE activity; little of which was pertinent to the project’s State focus. To address the State focus of the project more effectively, Avalere adopted a “filter.” Avalere applied the following “filter” criteria to all identified initiatives: 1) Did the project include State and/or Medicaid agency involvement through funding, program direction, or other means?; 2) Did the project target patients Statewide or target a large portion of patients across the State or in a specific area of the State; or 3) Did the project involve a Statewide Regional Health Information Organization (RHIO) or a RHIO-like construct with broad cross collaboration and stakeholder involvement? In addition, Avalere specifically excluded projects or initiatives that were contained solely within a single hospital or health system, as well as HIT projects that were primarily administrative or focused on reducing fraud and abuse, e.g., investments in States’ Medicaid Management Information Systems. For the balance of this report, the authors use the term “State-based HIE activities” to reference those projects that met the specified criteria and exclusions.

The authors based their analysis and selection of State projects for further review on available sources but did not conduct further research or analysis to validate the publicly available information beyond the case studies. Due to the absence of any standard reporting or tracking mechanisms for State HIE however, the actual degree and type of State involvement may vary. This study is not intended to be a comprehensive analysis of all HIE activity in the U.S. Nevertheless, there is significant ongoing HIE activity, and this report provides a valid snapshot of the projected goals, broad trends, and direction of this activity.

State-based HIE Trends: General Findings

Avalere’s environmental scan, using the State filters and public sources characterized above, identified 101 State-based HIE projects in 35 different States. The remaining 15 States likely have HIE projects under way but they may not be reflected in the publicly available aggregate reports or studies. Exclusions of these projects might be due to a number of reasons, including being in the early planning stages, having limited funding, or not publicizing their activities. Thus, because of the data limitations, the authors’ findings should be interpreted as capturing the lower threshold of State-based activity.

Despite the limitations of the data collection, there are a number of notable general observations regarding State-based HIE activities:

- Many States have multiple ongoing State projects ranging from a single project to upwards of 12 HIE projects;
- The numbers of projects appear to be linked to both the size of the State and how long the State has been engaged in HIE;
- No two projects are exactly alike nor are the roles played by the States;
- Only 19 of the projects actually mentioned Medicaid as a stakeholder;
- The technologies and initiatives most commonly sited across these projects are:
 - » electronic health records (EHRs);
 - » RHIOs to support HIE; and
 - » electronic prescribing (eRx) and medication management.
- Information on barriers, target population, stakeholder participation, and financing varies significantly, and is often unavailable.

Historically, the State has been only one of many participants in community-based HIE efforts. More concretely, the State’s involvement is often limited to a “simple vote of confidence” that the initiative is worthwhile. As described above, this report initially scanned available aggregate resources to identify HIE projects in which the State was an *active* participant. The available data is limited in its ability to capture the extent to of involvement by the various stakeholders. Oftentimes, if a State was mentioned, there was no other link or resource validating or elaborating on the role of the State. In each of these cases, where the State was mentioned as stakeholder (e.g., Department of Health, Medicaid, other State agency, or

involvement of the Governor or Governor's office) with no additional information on the extent of involvement, the authors' analysis included them in the review.

One of the report objectives, as noted earlier, was to examine HIE activity within the Medicaid program. It is evident from the broad environmental scan and from further analysis of the selected State-based HIE projects that activity within Medicaid seems quite limited. Avalere's research shows some experimentation in Medicaid, (Arizona and Tennessee's activities are highlighted in the Case Study section), along with the presence of some innovative Federal mechanisms intended to foster HIE and use of HIT such as 1115 Waivers, Home and Community Based Services Waivers, and integration with the Medicaid Information Technology Architecture (MITA). Measured against the level of HIE activities outside of the Medicaid space, there does not appear to be evidence of significant HIT adoption or HIE activities within States' Medicaid programs.

Despite this general finding, the research suggests that one of the most notable State-based HIE initiatives to date is in New York, where the governor plans to reinvest \$1.5 billion of savings gained under the State's 1115 waiver to improve facility infrastructure and to specifically promote HIT adoption and HIE. However, the NY plan is not sufficiently mature to permit a full understanding of the program or its impact.

State-based HIE Trends: Specific Findings

Maturity and Size Seems to Matter With few exceptions, most of the projects captured in this report are in nascent stages and are currently developing their strategies. The few notable exceptions of well-established projects (such as Indiana, as well as North Carolina and Utah highlighted in this report) are moving into implementation and evaluation stages, but projects at this advanced level of implementation remain sparse among the HIE landscape.

Avalere's research suggests that States with well-developed sets of relationships among key HIE stakeholders are further along in adopting sustainable HIE projects. Among the States that have been engaged in HIE for a longer duration, there seems to exist a strong foundation of trust among stakeholders that appears to help ease some of the legal and cultural barriers surrounding HIE. Smaller States may be better positioned to engage in Statewide HIE projects because their populations tend to be smaller and more centrally located, and there tend to be fewer health care stakeholders to coordinate. This is in contrast to larger States where there tend to be a greater number of large stakeholders, and a larger, more diverse and diffuse population base.

Projects' Target Populations Tend to Vary in Size and Type While some State-based HIE initiatives focus on connecting the entire State, Avalere also identified a number of activities that focus on smaller, harder-to-reach, vulnerable populations (e.g., people with asthma, chronic diseases). These activities tend to work closely with the States' Medicaid programs, and tended to target distinct sub-populations in an effort to improve quality, access, and the provision of cost-effective care for populations viewed as vulnerable. Medicaid programs may increasingly view HIE as a way to provide their beneficiaries a higher quality of care while managing costs.

RHIOs Are Many and Varied – With Minimal Inter-RHIO Coordination RHIOs, at the broadest level, are defined as multi-stakeholder organizations that work to support and enable the exchange of health information. RHIOs are emerging quickly among individual HIE projects. Many States have multiple RHIOs – many of which are only in the planning stages. There is no single entity model that characterizes a RHIO, and its participants, organization, structure, and activities are as varied as the communities represented.

Projects Tend Not to Identify Specific Settings of Care

Less than 10% of the identified projects focus on a specific care setting, such as emergency departments (ED) or ambulatory settings (e.g., community health centers). Generally speaking, specific sites of care may have an increased risk of high cost or potential for inconsistent quality of care, and thus could benefit from more effective information exchange and care coordination. Additionally, piloting data exchange in potentially narrow or specific settings may help to demonstrate early success and spawn HIE progress to other delivery settings.

“Home care agencies are a special entity because it makes sense for them to be sharing information with physicians and hospitals. The problems start when physicians, hospital, and payers view the information as proprietary and don’t see it [sharing data] contributing to their success.”

Projects targeting the long-term care (LTC) setting are noticeably underrepresented in the diverse HIT landscape. Despite an ageing population in need of more LTC and home health services, these care settings are not receiving comparable attention in the move toward an interoperable HIE environment. Only 8 projects even mentioned any consideration of patients in skilled nursing facilities or other LTC environments.

Most Projects Have Embraced Technology, with Considerable Variation Most of the identified projects specifically reference the introduction of one or more technological approaches to HIE. These include EHR, clinical data repository (CDR), master patient index (MPI), record locator service (RLS), telemedicine technology, eRx, technologies to support medication management, and disease or immunization registries. There also appears to be a high priority placed on CDRs by State-driven projects, perhaps to support their biosurveillance and public health tracking needs. It is clear that many different technologies are being deployed with no two projects utilizing the exact same infrastructure or technology.

Stakeholder Representation Is Varied: Providers Are Prevalent; Consumers Are Rare Hospitals, health plans, academic medical centers, integrated delivery networks (IDNs), and other providers are the most common set of stakeholders cited across the various HIE projects. Perhaps simply less visible, it appears that many stakeholders are underrepresented, including LTC, home health, rehabilitation facilities, consumers, laboratories, and a broad array of medical specialists.

Financing Details Are Limited Some level of funding information (either funding source or award amount) was available for a majority of the identified projects, with project funding levels ranging from \$200,000 to \$1 billion over 4 years. However, in most cases, details about the projects’ funding and financing strategies are inconsistent, incomplete, and often unavailable. It is also clear that most funding comes from Federal and State governments, followed by foundation grants and private sector financing.

The following eight case studies provide some insight into the complexities and differences of State projects and how these complexities are being addressed.

Case Studies

Based on the environmental scan, Avalere identified eight State-based projects to represent a cross section of HIE activity and conducted further analysis and an in-depth review, which is presented in following section.

State Selection

In selecting State initiatives for more in-depth analysis, Avalere sought to highlight a cross section of States and projects based on the following attributes:

- Progressive (e.g., more advanced or experienced)

- Innovative (e.g., demonstrated a novel approach or priority)
- Replicable (e.g., scalable project or initiative that was more narrowly focused and potentially easier for other States to implement)
- Geographically diverse (e.g., small, mid-size, and large States)
- Unique target populations (e.g., populations often not a focus of HIE projects such as LTC population).

Ultimately, Avalere selected HIE projects in the following States: Arizona, Florida, Hawaii, New York, North Carolina, Rhode Island, Tennessee, and Utah. Given the large and ever growing number of HIE projects across the country, the authors recognize that there are potentially many State and program combinations that would have met the established criteria. Nonetheless, these projects showcase a useful cross-section of States and activities at different stages, with different stakeholders, different funding mechanisms, different experiences, and different challenges. The detailed information provided on these varied projects will help give the reader a more comprehensive, accurate understanding of these select HIE activities, and will help to inform the ongoing dialogue on States' role(s) in planning and implementing HIE projects at the State, regional, and community level.

State/Project Similarities and Differences

One of the goals of this report was to examine various State-level HIE and HIT activities. Given the selection criteria for case studies, the authors anticipated a certain amount of variation. Nevertheless, certain inter-State similarities and differences emerged:

No Two Projects Are Alike Regardless of their similar goals, there is tremendous variation across the projects. The unique attributes of the States and their residents, the engaged stakeholders, available funding, community history, and the selected project(s) all contribute to these significant differences.

Timeframes for Implementation Are Often Underestimated When asked what a realistic timeframe is for implementation and data exchange, most States indicated two to three years, regardless of the nature or ambitiousness of their project. Given that many of the eight studied projects remain in the early stages of implementation, or more notably in the planning stages, this time frame may be optimistic and will likely be subject to additional external forces (e.g., funding and consensus building).

Emphasis on the Consumer Is Mixed Half of the projects studied identify a consumer focus either through outward facing technology (e.g., personal health record (PHR) or patient portal) which are still in the planning phases, or through participation in the HIE project (e.g., Consumer Council). Most of these projects are still working to identify and solidify the "right" type of consumer(s) and their role(s) in the context of project planning and implementation.

State Departments of Health Have a Seat at Every HIE Table With the exception of projects with a Medicaid focus, the State Department of Health (DOH) is the leading State government participant in the majority of States. The State plays a variety of roles in these projects including: the main cross-stakeholder facilitator; a primary driver of the project, particularly when it is a Medicaid project; a funding resource; and a data resource.

The State is seen as an objective or neutral convener and facilitator, particularly in the context of infrastructure projects. This is in contrast to large private sector stakeholders that are often perceived as having their own agendas. Most of the projects that are moving beyond enabling an infrastructure are seeking to select and implement manageable projects with tangible benefits that can be viewed as "early wins." All of the States see their goals and projects driven by the needs of the local community in which they are seeking to enable HIE.

"HIE projects must develop a community vision and a strong business value to secure vested community interest and develop trust among the many stakeholder entities."

The Role of the State as the Primary Leader May Be Time Limited Many of the State led projects anticipate becoming, or turning over primary HIE leadership, to a 501(c)(3) organization. This is likely due to the community and State desire to establish a self-sustaining model for cross-stakeholder HIE and ongoing collaboration. Additionally, some of the States' interests are not always viewed as consistent with the broader health care community. This ambivalence may be linked to the inherent challenges faced by States including: limited funding; the timeliness of State funding disbursements; the bureaucratic nature of government processes; and the bias or perceived bias in managing projects when the State is a major stakeholder (e.g., when the State funds certain activities to the exclusion of others).

Recognized Tension Exists Between HIE Promotion and Quality Measurement As States launch HIE projects, many are working to balance the recognized benefits of capturing and transmitting health care data to support quality measurement with the expressed concerns of providers and other engaged stakeholders against hasty adoption of specific quality measures. Some projects have purposely opted to exclude this "quality metric" component to minimize barriers to physician engagement.

Experience Equals Stakeholder Buy-In Some of the key differences noted across the selected States can be tied directly to variations in States' "time in the field." The more experienced States, i.e., those that have been fostering stakeholder dialogues and projects for several years, had broader stakeholder buy-in and encountered less resistance to enabling any particular project.

Funding Widely Varies but Ultimate Goal Is Long-term Sustainability Funding of individual projects ranged from \$50K to \$14.5M including in-kind support. In terms of State HIE funding across projects in a single State, New York surfaced as an outlier with \$1B in capital funds to promote improvements to the State's health care system. Most State and HIE projects rely on a mix of funding streams (e.g., Federal, State, foundation, in-kind) but all are seeking initial funds and models for sustainable funding. Regardless of the State, start-up funding and the quest for long-term sustainable revenue represent two of most significant challenges facing HIE projects today.

The individual case studies that follow give further insights into the similarities and differences across State projects. They identify issues that States are likely to encounter as they pursue initial HIE projects. Additionally, a broad array of HIE activity is highlighted including the variability of progress, stakeholders, technology, funding, and strategy. A primary goal in presenting these State-based case studies is to facilitate a better understanding of HIE activities nationwide and promote dialogue across States and other major stakeholders seeking to implement HIE projects in their own State and communities.



Arizona Health Care Cost Containment System Health Information Exchange

Dates of Note	<ul style="list-style-type: none"> 2005: Planning initiated
Overall Program Objective	<ul style="list-style-type: none"> Improve coordination and communication between the Behavioral Health and Physical Health Systems to improve the quality and efficiency of care for Medicaid patients.
Engaged Stakeholders	<ul style="list-style-type: none"> State Medicaid Agency Physicians Mental Health Providers (e.g., psychologists, nurses, physician assistants) Health Plans
Target Population	<ul style="list-style-type: none"> Arizona Medicaid patients receiving both behavioral and physical health treatment
Technology/Infrastructure	<ul style="list-style-type: none"> CDR updated semi-weekly Web-based interface
Funding	<ul style="list-style-type: none"> State—Medicaid, staff support, and \$50,000 in hardware costs
Timing	<ul style="list-style-type: none"> Planning phase under way; implementation and data exchange anticipated in July 2006
Unique Program and State Features	<ul style="list-style-type: none"> Medicaid-driven project Internally (Medicaid only) funded Emphasis on mental health Heavy managed care penetration

Overview

Arizona's Medicaid agency, the Arizona Health Care Cost Containment System (AHCCCS), is working to improve coordination of information between its physical and behavioral health providers and improve the quality of care for the Medicaid population. In Arizona, treatment for mental health is a carved-out benefit under AHCCCS that is administered under a separate DOH agency, the Behavioral Health System (BHS).

BHS receives funding from AHCCCS to provide behavioral treatment to Medicaid-eligible members. The existence of two separate systems has created challenges for physicians in serving AHCCCS patients who are treated for both behavioral health and physical health needs. A patient's behavioral health history is frequently unknown to the patient's primary care physician

(PCP) and the patient's medication history and other relevant information is often unknown to the treating behavioral physician.

To date, there has been no automated mechanism to exchange data between the BHS and the physical health systems under AHCCCS. In addition, there has not been a mechanism for physicians or other providers (e.g., nurse practitioners, physician assistants, psychologists) to easily communicate patient information (e.g., lab data, medication lists) and coordinate care. To address this, AHCCCS is building a CDR with a web-based interface to allow providers to access behavioral and physical health information, better understand the full spectrum of care their patients are receiving, and ultimately improve the coordination and quality of care for this patient population.

As an example, certain behavioral health medications can cause metabolic syndromes in patients with diabetes, which may lead to a deterioration of blood sugar control, even in previously well-controlled patients. However, oftentimes, the prescribing behavioral health physician does not have the ability to monitor the patient's blood sugars because AHCCCS only pays for glucose testing under the physical health system's benefit. Therefore, under the current process, if a behavioral health physician wants to track a patient's blood glucose, he or she must request the information from the patient's PCP and then wait until the PCP orders the test and returns the test results to the behavioral health physician. This PCP-focused process is intended to avoid unnecessary duplication of services by narrowing the number of physicians who can order tests on Medicaid members. Not surprisingly, this limited and cumbersome communication creates many

Timeline

May-June 2005

Initial planning of HIE project

July-September 2005

Focus groups convened

October 2005

Workgroup forms to evaluate possible technology solutions

July 2006

Technological implementation and data exchange anticipated

challenges for patients and providers, and is often inconsistent, inefficient, and frequently has led to problems with patient medication compliance (e.g., the patient does not receive a prescription or does not receive the correct prescription).

Planning and Implementation

Planning In light of the complex communication exchange and potential for ineffective or even inappropriate care, AHCCCS, together with physical and behavioral health providers, Medicaid health plans, and other interested parties, worked collectively to identify solutions to improve care coordination for Medicaid patients who also receive behavioral health care services. AHCCCS held a series of focus groups comprised of physicians, psychologists, nurse practitioners, physician assistants, patient advocates, and health plan leaders to accomplish four goals:

1. Better understand current practices;
2. Identify desired capabilities and data points for an HIE system;
3. Identify barriers; and
4. Determine how providers could move forward with a new HIE solution.

As expected, the focus groups confirmed the challenges of the current communication process, but also worked to understand preferred solutions and critical data needs. The dialogue revealed a preference for a technical solution that allowed real-time information exchange but it was clear that no entity wanted responsibility for data entry or database maintenance. Stakeholders identified the following data points as the most desirable for HIE:

- Patient demographics
- Health plan enrollment data
- Names/contact information for behavioral and physical health providers
- Medication history
- Lab data results
- Recent hospitalization data

As a follow-up to the focus groups, AHCCCS convened a workgroup to identify next steps, create a road map for HIE implementation, and select an appropriate technology to be deployed under the project. After evaluating several possible HIE solutions – and balancing the program's needs and desires with the reality of available funding – the workgroup chose to develop a CDR with a web-based user interface that will support online access from a physician's office.

The CDR system is expected to provide access to information at the point of care although the system will not support real-time communication between providers. Rather, the system will house information on patient demographics, medical history, and medication history – all of which were deemed essential for coordinating care between behavioral and physical health physicians. As the technology progresses, AHCCCS officials intend to create a

mechanism to allow physicians to enter a note or

other clinical information on a patient.

Implementation The new HIE project within AHCCCS is expected to improve communication between behavioral health and physical health physicians and will hopefully lead to more timely and comprehensive information exchange. Access to the CDR will be available at no charge through a web-based user interface to PCPs and specialists who treat patients served by both the physical health and behavioral health systems. Eventually, improved HIE within AHCCCS is expected to result in a number of major benefits. Adverse drug events will decrease, as providers are more informed about their patient's medications, and preventative care will increase because lab data will reveal pending health issues and promote proactive versus reactive solutions to health problems. Ultimately, AHCCCS envisions a data warehouse system that supports quality measurement, physician retrieval of relevant claims and encounter data, and patient-specific behavioral² and physical health information.

As AHCCCS moves forward, it is particularly cognizant of privacy issues and is developing a system to prevent any individual user from accessing the data warehouse directly. As currently envisioned, participating health plans, pharmacy benefit managers (PBMs), and contracted laboratories will feed data into the CDR. Under this design, however, only AHCCCS can retrieve data from the mainframe which will be transferred to a server semi-weekly. Physicians or their office staff may access the patient specific data by querying the server, but they will never directly interact with the data on the mainframe. This process will help to maintain privacy and security of the data and lessen the possibility of individuals accidentally manipulating or damaging the information warehouse.

Originally, AHCCCS intended to capture information only on the approximately 15,000 to 20,000 patients with severe mental illness. However, once

“One of the biggest barriers to overcome has been the tension between getting a system that would be ideal (ideal means it would have a lot more information and would include notes from all providers on what was happening with patient medically and behaviorally) and getting a system implemented in a short time that will function.”

the project began, AHCCCS determined that with only minimal effort, it could expand the population to encompass the approximately 100,000 (10% of the Arizona Medicaid population) patients enrolled in both behavioral and physical health. AHCCCS anticipates a growing demand for this service once it is implemented and expects only negligible additional costs to add new data and to expand this system to other AHCCCS patient populations.

To date, AHCCCS has engaged many health care stakeholders from across the State including its health plans and the behavioral health plans contracted with BHS. Additionally, AHCCCS has been committed to involving physicians in all aspects of planning. Both behavioral and physical health physicians were instrumental in the focus groups including articulating problems with the current system, identifying necessary information to effectively treat patients, and describing the ways in which they would like to receive this information. Program officials recognized early on that physician reluctance is a major barrier to HIT adoption. As such, AHCCCS is committed to maintaining provider involvement at all stages of planning. Interviewees indicated that provider outreach will continue throughout implementation to foster support of the HIE project within the physician community. AHCCCS also plans to actively engage physicians in beta testing the technology to ensure that the format is acceptable and user-friendly.

² Psychotherapy notes will not be made available on this system, because release of psychotherapy notes requires patient authorization.

Financing and Sustainability

In the short-term, facilitated through low-maintenance data transfers from health plans, PBMs, and labs, the sustainability of the initiative's technology will be relatively easy and inexpensive. However, the long-term development and fiscal solvency of the program is unclear.

This HIE project differs from the other projects highlighted in this report because it is currently funded entirely by the State's Medicaid program (AHCCCS). The initiative is also staffed by full-time AHCCCS employees, which is estimated to cost \$100,000 to \$150,000 in staff time. AHCCCS may also fund the anticipated \$50,000 in hardware costs necessary to support a separate stand-alone server. However, the program is currently in negotiations with BHS to evaluate if the two agencies can share these costs.

Looking at overall program costs, AHCCCS is considering the most cost-effective way to run the

program. They are conducting a cost-benefit analysis to evaluate whether it should be launched, supported, and housed within the State's Medicaid program. In particular, they are evaluating the costs of running the HIE project internally run, including staff time and hardware/software costs, as well as having the project managed exclusively through an external vendor. While there have been many vendors willing to provide AHCCCS with the "perfect system," the interviewees stressed the costs have been prohibitive. For example, the interviewees indicated that vendor solution costs are approximately three to five times the amount AHCCCS anticipates it will cost to house and run the technology internally.

It is currently unclear if AHCCCS has sufficient administrative funds to launch and maintain this project and may ultimately consider applying for public and/or private sector funding.

Challenges and Lessons Learned

The interviewees identified several barriers, which are also often cited by other HIE projects. These include resistance to change (especially when dealing with multiple agencies), privacy and security issues, and information maintenance responsibilities. AHCCCS program officials experienced stakeholder resistance to populating the CDR, and neither the physical nor the behavioral health departments had complete information to update it. Furthermore, AHCCCS experienced reticence when trying to persuade the different providers to enter or maintain patient information in the database. As a result, AHCCCS decided to use claims information² and readily available health plan and PBM encounter information³ to populate the database.

However, AHCCCS has experienced difficulty in identifying and "pulling data" to populate the database. They also recognize that programming and data retrieval becomes increasingly complicated with more information and search criteria.

"Use more limited projects to demonstrate early success."

AHCCCS is currently working with other stakeholders to identify from where pharmacy, lab, and demographic data should be retrieved.

The interviewees acknowledged that its initial successes will help it build a coalition of supporters and increase awareness of the value of HIE. AHCCCS credits much of its current momentum to the agency's relationship with the State, and with a variety of stakeholders—physicians in particular. AHCCCS also believes that smaller demonstration projects, which involve a manageable subset of the AHCCCS population, will be helpful for them moving forward. With increased support, stakeholder involvement, and demonstrated success, AHCCCS hopes to expand beyond its initial population to help foster the adoption of HIE more broadly.

Spotlight on State HIE Activity: Arizona

- *Collaborative group in southern Arizona* is in early discussions on developing a record-based platform for the exchange of medication, laboratory, procedure, and advance directive information.
- *Arizona 2-1-1* is part of a homeland security plan for the State. It consists of a Statewide database designed to give the public instant access to health services and emergency response information.
- *Regional center for border health* is focused on insurance and medication history for 600 patients and spans the US/Mexico border.
- *The Arizona Health Query* gathers de-identified data from programs across Arizona, including AHCCCS, to examine prevalence and outcomes and to support quality and public health evaluations. Ultimately, the Arizona Health Query will also include information from the Arizona Health Value Measurement Initiative, a consortium of major payers and employers including HSAG, LeapFrog, Bridges to Excellence, Intel, and IBM focused on creating a standardized measurement system that will produce performance reports.

Statewide Convener

The Governor's Initiative, which began with Governor Janet Napolitano's executive order, intends to implement EHRs in Arizona by 2010. In 2005, Governor Napolitano created a steering group representing over 40 public and private sector entities. She charged the group with developing a roadmap to outline EHR implementation in Arizona over the next five years. Working with support of the State, industry, health plans, hospitals, physicians, and private sector entities, the Governor has created a government-industry partnership to serve as a catalyst for the advancement of HIT in Arizona. The Governor's Initiative has also enlisted the support of eHealth Initiative's Janet Marchibroda, who

serves as senior faculty and de facto advisor to the initiative.

AHCCCS is participating fully with the Governor's Initiative and plans on merging its HIT efforts with the Governor's Initiative at the appropriate time. In the short term, AHCCCS will proceed in developing its own infrastructure until the Governor's Initiative is farther along. At that point, both parties will evaluate the benefits of integration and will likely merge proves to be more efficient and effective for all involved. Currently, the Governor's Initiative is still very much in the conceptual and planning phase, although eventually it is intended to function as the single entity coordinating HIE projects across the State.



Florida Health Information Network (FHIN)

Dates of Note	<ul style="list-style-type: none"> ■ 2003: Governor’s Taskforce called for increased EHR adoption ■ 2004: Governor’s Health Information Infrastructure Advisory Board created ■ 2005: FHIN, Inc. created
Overall Program Objective	<ul style="list-style-type: none"> ■ Improve the quality of care for patients treated in Florida by facilitating the exchange of clinical data between health care providers.
Engaged Stakeholders	<ul style="list-style-type: none"> ■ State Government including Medicaid ■ Physicians ■ Hospitals ■ Payers ■ Employers ■ Vendors
Target Population	<ul style="list-style-type: none"> ■ Statewide
Technology/Infrastructure	<ul style="list-style-type: none"> ■ Central server ■ MPI ■ RLS ■ Web services ■ Initial project – connect multiple RHIOs
Funding	<ul style="list-style-type: none"> ■ State Appropriations—\$1.5 million
Timing	<ul style="list-style-type: none"> ■ Pilot programs to be funded in 2006; Timing of FHIN infrastructure implementation unclear and dependent upon broader funding
Unique Program and State Features	<ul style="list-style-type: none"> ■ State agency-led initiative with strong Governor support ■ Many seasonal residents (“snowbirds”) create long-term rationale for HIE ■ Ten existing local RHIOs ■ Local and national focus

Overview

The Florida Health Information Network, Inc., (FHIN, Inc.) is a non-profit corporation created in April 2005 and charged with implementing a Statewide HIE infrastructure, the Florida Health Information Network (FHIN). In its *Interim Report*, issued February 2005, the Health Information Infrastructure Advisory Board (the Board), which was established in 2004 pursuant to an Executive Order issued by Florida’s Governor Jeb Bush, recommended the creation of the FHIN. The Board advises Florida’s Agency for Health Care Administration³ (AHCA) as

it develops and implements a plan for promoting EHR adoption and explores strategies for building and operating an effective and secure health information infrastructure in Florida. In doing so, the Board, which is comprised of 13 individuals including physicians, sought the advice of national experts and many Florida stakeholders, including physicians, provider institutions, consumers, payers, and purchasers of electronic health information systems.

As conceived, the FHIN will interconnect health care providers (physicians and hospitals) across

³ AHCA is responsible for the collection of State level health statistics, the administration of Florida’s Medicaid program, and the regulation of health facilities and managed care organizations throughout the State.

Its mission is to ensure accessible, affordable, quality health care for all Floridians.

Timeline

August 2003

Governor's Task Force on Access to Affordable Health Insurance created, calling for utilization of electronic health information and development of EHRs

May 2004

House passes Bill 1629 requiring AHCA to develop and implement a strategy to adopt and use EHRs

May 2004

Governor creates Health Information Infrastructure Advisory Board

Summer-Fall 2004

Board actively sought advice on electronic health information systems from national experts and Florida stakeholder groups

2005

Board issues First Interim Report to the Governor with preliminary strategic framework; recommends key actions for advancing the FHIN

January 2006

FHIN announces grants

Florida to facilitate the sharing of health care data without regard to where in the State the consumer

Planning and Implementation

Planning In 2005, AHCA applied for one of the National Health Information Infrastructure contracts from the Office of the National Coordinator. While Florida was not chosen as an award recipient, the interviewee Stated that the application process itself served as both a learning and consensus building exercise. Through the grant writing process, AHCA became more effective in bringing together various stakeholders, and the exercise left behind a well thought-out roadmap for future action in Florida.

In the face of not receiving funding for the contract, the Board recommended that AHCA, through its established public-private partnerships, pursue a controlled "launch and learn" approach and immediately begin FHIN development. The Board

resides or where health care services were delivered. This is particularly necessary given that many people in Florida are only seasonal residents. It also represents a collaborative effort between State government, the private sector, and at present ten RHIOs⁴ and HIE projects focused on serving Florida residents, all committed to participating in the FHIN. The target population for access to FHIN's information includes both providers and patients alike, but may vary from RHIO to RHIO depending upon their specific target population. For the near term however, AHCA will take the lead in promoting and managing the FHIN, as there will be a lag between AHCA's current responsibility to move State information exchange activities forward, FHIN, Inc. funding, and FHIN, Inc.'s ability to operationalize and carry out its charge to implement Statewide HIE.

The FHIN infrastructure is currently in the planning phase and not yet operational. While formal relationships with vendors have not yet been forged, AHCA is working with interested vendors to the extent that they are willing to provide input into the development of FHIN's technical infrastructure.

⁴ These ten RHIOs and HIEs include: the Tampa Bay RHIO, the Big Bend RHIO, the Northwest Florida RHIO, the Central Florida RHIO, the Health Care District of Palm Beach County, the Health Foundation of South Florida, Health First in Brevard County, the Pinellas County Health Department, Good Health Network in Maitland, and JaxCare in Jacksonville.

explicitly expressed interest in collaboration and are ready to implement pilot projects.

FHIN is actively working toward achieving its short and long-term goals. In the short term, FHIN will focus heavily on existing pilot projects and new subcontracts to ensure these projects are functioning effectively, even before the FHIN infrastructure is complete and ready to support interconnectivity across local and regional initiatives. In the long term, FHIN's vision is to be a secure network that makes necessary medical information available to authorized parties, including provider organizations, physicians, and patients.

In addition to developing a plan for implementing the FHIN infrastructure, the Board also recommended the State promote EHR adoption among Florida physicians. AHCA's strategy to increase EHR adoption is likely to include many projects focused on reducing physicians' financial and business risks in purchasing EHRs, promoting education and training on the use of EHRs, and structuring financial incentives, such as increased

reimbursement, to encourage physician adoption. The Board also recommended that the State partner with a broad array of stakeholder groups, in particular physician associations, to add greater momentum to these endeavors.

The FHIN's architecture should allow it to serve as the Statewide coordinating body for HIE. For example, vital clinical information in Medicaid's encounter database, electronic records of larger health care providers such as hospital chains and associations of community health centers, and the State's childhood immunization records will ultimately be shared Statewide. Medicaid and Medicare are also viewed as critical data sources for the FHIN. Their information will be available under the FHIN for the benefit of all Florida residents regardless of whether or not they reside in one of the participating health care markets. FHIN expects to significantly improve continuity of care, particularly for Florida's seasonal residents who may see multiple providers in different locales throughout any given year.

Implementation To date, AHCA has only been tangentially involved in the existing pilot programs through limited outreach and technical assistance. Moving forward, AHCA will likely be more engaged as the Board recently approved grant applications for nine projects. The grants, totaling more than \$1.5 million, are designed to facilitate the adoption and use of EHRs in Florida and will provide funding for planning, implementation, training, and technical assistance. Planning and implementation projects are designed to promote HIE among two or more competing provider organizations and to demonstrate the appropriate sharing of health information in the course of patient care. Training and technical assistance grants are intended to increase the number of practitioners using EHRs and participating in information exchange. According to the interviewee, these projects will eventually become part of the FHIN.

By initially piloting smaller scale information exchange projects, FHIN expects to be more successful in demonstrating its value and portability to other locations across the State and eventually to other networks across the country. The interviewee

noted that this incremental approach should help establish a clear and trusted business model that will also encourage broad stakeholder involvement.

While the overarching goal of FHIN is to support access to and exchange of all relevant health care information, the initial core data set will be hospital inpatient and outpatient encounters, laboratory results, medication history, diagnoses, and demographic information, all accessed at the local level. AHCA, through its extensive database of inpatient and outpatient data in the State Center for Health Statistics, intends to provide physicians with a historical record of care. AHCA also maintains all data for the Florida Medicaid program, which includes Medicaid patient claims information, demographics, visit dates, diagnoses, and medication claims. Moreover, AHCA plans to work with other State agencies, including the DOH, to make public health data available through the FHIN.

To support FHIN's data exchange and infrastructure goals, AHCA plans to construct a federated architecture network. With this type of network, data will reside locally but can be linked together and used globally to support data exchange across

the multiple RHIOs. The central server, which will be maintained by FHIN, Inc. will hold a MPI, a RLS, and software designed to query database servers maintained by the individual RHIOs. When a physician or provider organization queries patient information, that request is sent to the RHIO and the FHIN to retrieve the information. The FHIN then sends the query to other HIE projects in the State and ultimately to other health information networks in the country to gather the most complete information possible. This strategy of locally residing data was selected to give local RHIOs the greatest flexibility in implementing their own community-based HIE initiatives, and allows AHCA to leverage the RHIO's existing investments in planning and technical development.

Whenever possible, the FHIN will utilize the local stakeholder's existing connectivity, data storage

Financing and Sustainability

“Already, the RHIOs are saying that they need the FHIN to operate and set standards to ensure that their current efforts will be compatible with the overarching FHIN.”

Currently, FHIN does not have an ongoing revenue source or sustainable business model. The Florida State Legislature appropriated \$1.5 million to AHCA for FY2006. While this funding will not be sufficient to completely build the FHIN, the interviewee stated it was instrumental for promoting HIE projects in Florida. The funding will be used to support further development of the network's infrastructure, encourage local RHIO development, and give seed money to Statewide HIT pilot projects. Specifically, this money will support FHIN grants which will likely fund health-related organizations seeking assistance to plan, deploy, and evaluate interoperable HIE projects as well organizations working to encourage provider adoption of EHRs.

In the future, it is possible that FHIN, Inc. may administer the grant program. This will likely give it additional leverage and help to ensure that local organizations have direct incentives to adhere to FHIN standards. The Board also plans to support State wide efforts to secure funding for all Florida

capabilities, and interface standards. AHCA selected a portable and scalable web services interface to support communication between the Statewide and regional servers. Moving forward, new RHIOs participating in the FHIN must employ a similar architecture and web interface to be compatible with the existing architecture.

AHCA believes that with the FHIN infrastructure in place, physicians and provider organizations will be encouraged to adopt EHRs. Additionally with a greater number of authorized parties sharing health information on the network, the relative value of the network will increase for each stakeholder. AHCA expects this increase in utility to further attract network participants, and in turn make the FHIN more valuable and ultimately more sustainable for its users.

HIE projects. In partnership with ACHA's State Center for Health Statistics, the Board is developing a grants resource webpage to post HIE relevant Federal, State, and private grant opportunities.

The interviewee believes that moving forward, a balance will need to be struck between providing seed money and encouraging applicants to identify a sustainable funding model for themselves to reduce financial dependency on the State. Nevertheless, with respect to the FHIN, AHCA sees the State as a longtime funding partner.

Largely dependant upon available funding, AHCA would like the FHIN infrastructure to become fully operational in 2006. AHCA sought Federal grant funding, but to date has been unsuccessful. Currently AHCA is working with some of the State's legislative staff to develop appropriations legislation to support additional FHIN funding. The interviewee believes a private sector match provision will be necessary for it to receive political support. Working with major payers in Florida, AHCA is also garnering buy-in and soliciting additional funding but believes that a State commitment will be required to encourage private sector financial support. In 2006, Governor Bush is expected to request \$5 million in recurring funding for additional grants to support the expansion of EHRs and the

hiring of additional staff to support the FHIN and the grants program.

Currently, AHCA is communicating with RHIOs across the country to gain insight and identify sustainable business models that could be applied to the FHIN. AHCA is considering a membership dues model where fees vary based on the differentially accrued value to each stakeholder, but have not made any formal decisions. Ongoing

partnerships with payers, provider institutions, and investors are seen as necessary to support long-term sustainability of the FHIN. Also, given the critical importance of Medicare and Medicaid data to the utility of the network's users, the interviewee indicated that it would be ideal if these programs would fund the FHIN to support their own access to the information and support efforts to make the data accessible to other FHIN users.

Challenges and Lessons Learned

For Florida, there are several large obstacles to fully implementing the FHIN, including:

- Absence of a proven and sustainable business model;
- Low rates of HIT and EHR adoption;
- Overarching technical challenges and barriers such as:
 - » Building a MPI and RLS to correctly identify patients
 - » Presenting data in a meaningful way for physicians
- Legal and regulatory issues with existing privacy laws;
- Innate competition across health care stakeholders; and
- Lack of an existing HIE infrastructure.

Interviewees acknowledged that local HIE projects are hesitant to engage because there is presently no true consensus around data standards for information exchange. To help address this challenge, AHCA is currently drafting a White Paper on interoperable standards for national distribution with the intent to highlight the benefits of interoperability and encourage HIE projects to move in the same direction on standards. Interoperability and common standards are priorities for AHCA even in the absence of an interoperable infrastructure. The interviewee stressed the importance of these issues noting that all State-based HIE projects [in Florida] not only want to understand the “language” they should use in establishing HIE, they also want to be assured that over the long term, their systems will be able to integrate and communicate with other systems.

AHCA also understands that State or State-level entities are essential in convening and facilitating

“According to AHCA, the challenge is to develop a compelling mix of clear and immediate benefits to motivate stakeholders to participate in the migration to a model of health care based on an effective, integrated information system.”

collaboration amongst varied stakeholders. For example, early on, the Governor's Advisory Board encouraged stakeholder involvement and actively solicited input on how best to develop the FHIN infrastructure. The interviewee stressed the importance of having a neutral body at the helm of the project and of viewing the State as “an overseer of cooperation, to encourage and push for different entities to work together towards a synergy of data.” Because the State can take a broader view and bring diverse stakeholders to the table, it can also help these same stakeholders work together to find solutions. This process of developing a core group of interested and engaged stakeholders has been essential and beneficial to the development of Florida's initiative and will be important to maintain moving forward.

While there has not been a single stakeholder group that has served as the major driver of the FHIN, payers and provider organizations have played a central role. In particular, payers have expressed a willingness to participate in the FHIN as a data source. The interviewee, however, commented that more stakeholders need to be brought in, and noted that LTC stakeholders have not been involved to a large extent but will be involved in the future. The interviewee also acknowledged that

while consumers are currently targeted for active engagement and FHIN hopes to eventually provide direct engagement through a patient portal, consumer input could be solicited in the short term through surveys.

In addition to the State's encouragement of broad stakeholder engagement and collaboration, the

interviewee noted that Florida's early collaborative ONC grant writing experience created a cooperative and focused group of invested RHIOs, and helped identify shared goals and a more definitive strategic plan for HIE engagement. The process was beneficial and left Florida with a roadmap for moving forward in HIE.

Spotlight on State HIE Activity: Florida

- *Big Bend RHIO* will facilitate the exchange of patient data across multiple health care providers in the Florida Big Bend area.
- *Tampa Bay RHIO* will create technical and clinical pathways to improve the quality and availability of health information, targeting persons with diabetes, asthma, and proState cancer.
- *Palm Beach County Community Health Alliance and the Health Care District of Palm Beach County* will plan, design, implement, and evaluate a shared EHR model for record sharing among a core group of safety net providers in Palm Beach County.
- *AccessEscambia* represents a group of local providers collaborating to design an interoperable health information system that will permit users to exchange critical patient information in a standardized format between non-affiliated hospitals, clinics, laboratories, pharmacies, and physician offices in Escambia County Florida.
- *Central Florida RHIO* will create a plan for a working RHIO model that will demonstrate IT connectivity among health care providers and an approach for achieving long-term sustainability.
- *Brevard County Health Information Network* will outline the specific actions required to implement a technology based health information network that links non-affiliated health care providers in Brevard County.
- *South Florida Health Information Initiative* will develop an organization structure that is inclusive of the health care provider, payer, IT, consumer, advocacy, and business community in Miami-Dade and its surrounding counties.
- *Pinellas County Health Department* will develop a comprehensive action plan for supplying additional clinical and public health chronic disease information and data to the Tampa Bay RHIO.

Statewide Convener

The Board and AHCA acknowledge the need for a single entity to support collaboration and coordination across the broad array of Statewide HIT projects. They expect FHIN, Inc., once operational, to serve in this role. The Board believes the overarching goal of FHIN, Inc. is to bring together all of the various health care markets in Florida and to serve as the main coordinating body for HIE projects in the State.

AHCA is currently working to facilitate coordination across HIE projects, but is not assuming the formal role of a Statewide convener. Moving forward, it is Florida's hope that FHIN, Inc. will be viewed as a

neutral third party, separate from the State, and will coordinate and collaborate with the State and other health care stakeholders. FHIN, Inc. will not be funded or supported by any single organization but instead will work with and across all stakeholders on infrastructure, programmatic issues, technical developments, and funding. Florida is still examining the array of roles for FHIN, Inc. but ultimately it may also serve as a standards-setting body, a resource and educator for Statewide activities, and a funder of grants that support State HIE projects.



Quality Healthcare Alliance (QHA) Health Information Exchange Network

Dates of Note	<ul style="list-style-type: none"> ▪ 2003: QHA established ▪ 2004: HIE Network launched
Overall Program Objective	<ul style="list-style-type: none"> ▪ Provide access to timely, reliable health information which will increase efficiencies, improve clinical outcomes, and lower costs.
Engaged Stakeholders	<ul style="list-style-type: none"> ▪ State Government ▪ Physicians ▪ Physician Associations ▪ Hospitals ▪ Business coalition ▪ Health Plans ▪ Employers ▪ Consumers ▪ Research Organizations ▪ Vendors and Consultants
Target Population	<ul style="list-style-type: none"> ▪ Statewide
Technology/Infrastructure	<ul style="list-style-type: none"> ▪ CDR ▪ EHR ▪ eRx ▪ Electronic Laboratory Reporting (eLab) ▪ Unique Patient Identifier Number (UPIN) ▪ Patient Portal ▪ Employer Portal ▪ Initial project – implement multiple applications in a small region
Funding	<ul style="list-style-type: none"> ▪ Initial member donations—\$80,000 and in-kind support ▪ Federal—\$500,000 ▪ Subscription and data source fees ▪ Data sales for research ▪ Anticipated State and additional private sector funding
Timing	<ul style="list-style-type: none"> ▪ Implementation of EHR and CDR under way in select physician groups on Maui; roll out will continue in 2006 across physicians groups islandwide and expand to neighboring islands in 2007 and beyond
Unique Program and State Features	<ul style="list-style-type: none"> ▪ Heavy physician and business leader involvement ▪ Large rural population with geographic disbursement ▪ Health insurance mandate for all Hawaii employers ▪ Consumer (patient portal) and employee wellness focus ▪ AHRQ implementation grant recipient ▪ Discounted single vendor solution

Overview

The Quality Healthcare Alliance (QHA), established in 2003, is a non-profit consortium of health care stakeholders and State and local government agencies in Hawaii whose vision is to transform

health care to a patient-centered care model that will drive quality care. QHA recognizes the importance of providing information to the patient as a tool for managing health and understands that

access to timely, relevant, reliable, and secure health information is the missing link in supporting patient centered care.

QHA's vision of a Statewide HIE network acts as a catalyst for transforming health care where quality and wellness, not illness, is the focus. The idea to create an HIE network actually dates back nine years, to a group of Hawaii physicians. At the time, these physicians were unable to garner support or a commitment from the necessary stakeholders, nor did they possess the business expertise to organize, build, or implement an HIE project. Years later, the business community came together with a shared vision for improving the health care system and a belief that costs could be effectively managed by focusing on quality.

Toward this end, business leaders, technology experts, and physicians from the Hawaii Medical Association, the Hawaii Independent Physicians Association, the Hawaii Business Health Council (HBHC)⁵, and the Medical Exchange of Hawaii formed QHA to transform health care in Hawaii through HIE. Notably, QHA recognized the importance of representing all market segments and spent its first year engaged in collaborative discussions across all major stakeholder groups, with an emphasis on including physicians. Since its inception, additional industry leaders, government agencies, and legislators have joined QHA. Its current Board includes a patient/consumer representative, and a Medicaid and a Medicare representative. As a result of its early outreach and collaborative efforts, QHA has engendered the support and trust of the business and health care communities.

The HIE network and supporting infrastructure will be a CDR with interoperable EHRs accessible by the internet or a VPN that will capture and support exchange of clinical, administrative, and claims data. The systems will be flexible to allow

⁵HBHC represents a cross-section of most industries in Hawaii.

Planning and Implementation

Planning Initially, QHA established workgroups and committees to identify governance roles, and to plan and manage the HIE networks' development and operations. With input and coordination

Timeline

2002

HBHC creates HIE model and writes business plan

January 2003

HBHC joins with Hawaii Medical Association (HMA) and the Hawaii Independent Physicians Association (HIPA)

May 2003

HBHC, HMA, and HIPA hold Statewide conference crafting an agreement to build an HIE model measuring clinical outcomes; QHA established to implement

August 2003

QHA builds goals and clinical measures

September 2003

Measures adopted; QHA adds legislators, health plans, government agencies, labor unions, and regulators

2004

HIE network planning and collaboration development

2005-2006

Roll out to Maui

interconnectivity and interoperation with stakeholders' legacy systems, as well as provide real-time access and reporting. The network will also support a patient portal and PHRs.

Ultimately, QHA intends to target Hawaii residents Statewide although it currently separates its target population into three major segments: 1) employees and dependents of HBHC companies and labor union members covered by commercial health plans; 2) Medicaid population; and 3) Medicare-eligible population.

from all stakeholders, QHA developed the following seven guiding principles and overarching goals to articulate a clear vision and provide direction for the initiative moving forward:

1. Improve the quality of health care for QHA beneficiaries;
2. Support continuous quality improvement through identification and measurement of meaningful quality indicators, and through strategies to improve patient care;
3. Implement technology to allow point of care, data collection and documentation;
4. Commit to collaborative working relationships with the broadest range of health care stakeholders (e.g., ancillary services/providers, patients) to provide the highest quality of health care possible;
5. Align financial incentives for all stakeholders to produce a health care reimbursement system that focuses on clinical outcomes improvements, not episodic care;
6. Provide educational resources, counseling, guidance, and motivation to Hawaii patients to embrace their responsibility for improving their own health status; and
7. Redefine the term “healthy State” to include all aspects of health status.

To address the diverse challenges in health care and to accomplish these goals, QHA intends to support and implement a number of HIT projects and programs across the State, including a UPIN, MPI, EHR, eRx, electronic laboratory (eLab) result reporting, and an incentive system for patients and physicians. Today, many of these initiatives are still in the planning phase.

Statewide Unique Patient Identifier Number (UPIN)

A UPIN will be assigned to each eligible individual across the State and will remain with that patient for life. The HIE network will maintain a database with all UPINs, with required patient demographic information, to ensure a duplicate UPIN is not assigned. Medicaid and Medicare beneficiaries will be assigned UPINs at the time their respective health insurance cards are distributed. Similarly, Hawaii employers will assign UPIN numbers for their employees and their dependents. The UPIN is initially being rolled out on Maui.

Electronic Health Records and Clinical Data Repository EHRs that include eRx and eLab components will be launched as part of the HIE network, to provide secure access to timely, relevant, and reliable health information for patients and care

providers throughout Hawaii. QHA intends to populate EHRs with baseline data from health plans and subsequently will allow patients to submit personal health histories. Additionally, QHA will use EHRs to capture encounter data, i.e., patient visits to clinicians across care settings to yield a thorough historical record of care for every patient in the State.

To promote EHR adoption, QHA is working with a single vendor to negotiate a low-cost EHR technology and a local and Statewide CDR that services the QHA network. Physician groups can operate their own CDR or EHR, or they may opt to access the system through their VPN. The CDR will be interoperable with other EHR solutions so as not to limit physicians' choices or constrain their options, but QHA hopes a low-cost EHR will encourage physicians to select the State vendor system.

Electronic Laboratory Result Reporting QHA expects the electronic reporting of lab results, included as part of the EHR, will form the foundation for measuring improvements in clinical outcomes. Initially, evidence-based clinical measures for diabetic and cardiac disease will be reported to physicians on an individual patient basis and to the State for population health. Automated lab test reminders will facilitate compliance with clinical guidelines, and a centralized location for viewing results will reduce duplication of services and provide timely information and decision-making tools for care across provider settings. The centralized viewing location will be a function of the CDR while the reminder feature will be part of the EHR.

Patient Portal A patient portal will allow patients to view their EHR and will enable secure access to their clinical record, medication history, and lab results. The portal will also allow patients to add, access, and work with the data from the Worksite Wellness Program (described below) that resides in their PHR. QHA is in the planning phase and is identifying a vendor for this feature.

Incentive Systems for Patients and Physicians

Once the processes and technology infrastructure are in place for robust clinical data capture and exchange, QHA will implement incentive systems for employees and physicians to support the broader goal of improving quality of care and health outcomes.

- For the employees, the Worksite Wellness Program (WWP) will encourage the patient to become a partner in his or her health care team. It will provide disease or condition-specific educational resources, motivational information, and models for setting and reaching attainable health goals. If the patient agrees, data collected from the WWP will be entered into a PHR through a secure Internet connection. Patients may also grant physicians access to historical health data not previously part of routine visits.

This prevention program was promoted by employer stakeholders who understand that a key element to reducing health care costs is tied to individual consumption of health care services. QHA's members share the vision that healthy employees increase productivity in the workplace and reduce costs for the overall health care system. Currently, QHA is in the process of implementing a diabetic life coaching model and a module of WWP for employers to improve patients' lifestyle choices through one-on-one interventions.

- For physicians, a pay-for-performance system built on the Bridges to Excellence (BTE) program will work to encourage better health care

by financially rewarding physicians who implement and use HIT to deliver safe, effective, and high quality care. Physicians who demonstrate good performance in a set of identified areas will be paid bonuses by participating QHA employers.

The HIE project has been driven heavily by the Hawaiian business community, although the HIE network has a broad base of engaged stakeholders. Despite their outreach efforts, QHA and the HIE network still struggle to engage small physician practices across Hawaii. The interviewee attributes this to physicians' lack of readiness for change and their apprehension to the potentially significant financial and operational burdens that lie ahead for their practice. Additionally, the interviewee noted that the State Medicaid office is currently "waiting and watching" and will likely participate in the project once program officials are convinced that HIE implementation on Maui is successful. The interviewee anticipates Medicaid's role as a future funder of the initiative and indicated that the HIE project will also consider integration opportunities with the Medicaid Information Technology Architecture (MITA) in the longer term.

Implementation Implementation of the HIE network will occur island by island across Hawaii in a four-phased approach beginning on the island of Maui. The roll out will transpire over 2006, with the goal of full information exchange for eRx, eLab, and other clinical data sources related to the EHR by the end of 2006. The focus will be on information exchange and implementation of all of the supporting technology infrastructure components. Through dialogue with physicians and input from other stakeholder groups, QHA believes that by limiting the initial implementation to Maui, they can build and strengthen the 'proof of concept' as they move forward on Hawaii's other islands.

- Phase I: Roll out to Maui
QHA anticipates implementation will occur in the following order:
 - Obtain participation agreements with employers, patients, and physicians
 - Assign UPIN

"In order to be successful you need a champion in the marketplace with clout to motivate people and create action – for QHA this has been the employer community."

- Roll out EHRs, including eRx and eLab functions across physician offices
 - Implement the CDR
 - Launch patient portal
 - Establish physician and patient incentive programs
- Phase II: Roll out to Big Island
 - Phase III: Roll out to Kauai
 - Phase IV: Roll out to Oahu

QHA's HIE project, currently in phase one, is implementing EHRs in a 40-person physician group on Maui. This island was chosen for the first phase because it was deemed the most ready for change—half of the physicians on Maui were

motivated by business reasons to embrace HIE. In particular, a number of these physicians anticipated that participation in the HIE project would allow them to gain a competitive advantage and were compelled to “catch up” to some of the existing HIE efforts under way by the island’s single largest provider and payer.

As part of phase one, QHA is defining the appropriate data sets and decision support models that physicians will need and use as part of the EHR. Additionally, QHA is building a Continuity of Care Record (CCR) that will help the CDR vendor enable interoperability with many EHR platforms. The interviewee noted that the clinicians are the “developers” of the CCR. They will determine what data elements are included in the CCR and will also

assess the need for the CCR to access physician EHR data. The CCR will have a UPIN data field that will assemble information from multiple providers for a given patient; the eLab, eRx, and other systems will also use the UPIN as the common identifier.

QHA will connect Maui physician practices one at a time throughout the implementation phase. As practices become interconnected, they will also gain access to the CDR and to better and more comprehensive information at the point of care. The interviewee indicated that improving quality of care is the overarching purpose of the CDR and the CCR, and he believes that physicians who are interested in the quality of care vision will participate.

Financing and Sustainability

QHA’s initial program support was derived from a funding pool that included \$15,000 from each of its founding members for a total of \$80,000 and a \$500,000 AHRQ implementation grant. Despite being chosen as a finalist in the Foundation for eHealth’s granting process, QHA was not selected as an award recipient.

In developing its sustainable business model, QHA is taking a long-term perspective. The philosophy underlying QHA’s business model is based on the theory that controlling resource consumption will generate savings in health premiums which may then be reinvested in the HIE network. QHA believes that its business model of all parties having a vested interest in ensuring the success of the HIE network, is a means for perpetuating sustainable funding. The capital needs of the project will be distributed across stakeholders according to benefits accrued to each stakeholder category. Those stakeholders with the most to gain from the improved clinical outcomes yielded by HIE will bear a higher burden of expenditures. This approach is one of QHA’s guiding principles and enjoys widespread community support.

Beginning sometime in 2006, QHA intends for each HIE user to pay a subscriber fee, which initially will represent a significant percentage of the HIE network’s revenue. Four categories of subscriber fees will be implemented: 1) physicians and allied health

professionals; 2) hospitals and LTC facilities; 3) patients; and 4) employers. The fees for each category and the annual justification for the fee amounts will be decided by QHA’s Board of Directors.

As part of QHA’s model, physicians will pay to access lab results and eRx. Patients will pay to access their health records and health education resources for the creation of detailed individual health improvement plans, and for the ability to communicate via email with their providers. Employers will pay a fee for aggregate clinical data on their population and will pay to participate in the WWP to benefit from lower premiums and less time lost to sick leave. In addition, payers will participate at no charge by providing baseline data on all patients to the consortium in return for the reduced number of claims they expect to see as HIE occurs. As HIE services are added over time, the subscription income is expected to increase.

Another source of QHA’s income will be generated by selling de-identified clinical data from the CDR to research organizations, medical data warehouses, medical supply manufacturers, and pharmaceutical companies. These data sales will be charged per record transmitted. If the patient and the provider do not provide written consent to sell those records, the records will not be available for sale. Over time, the value of de-identified data to

these purchasers is expected to increase, as a de-identified patient record with 10 years of history will be worth more to researchers than one year's worth of data. Currently, QHA is partnering with a pharmaceutical manufacturer who is also a QHA member, on a clinical research study examining drug compliance. This project is expected to provide QHA members with valuable clinical information and will also test the viability of selling clinical data as a revenue source. Income from the sale of de-identified clinical data for research purposes is anticipated in 2007.

In addition to the initial funding, QHA identified a variety of other public and private funding sources and is currently initiating discussions with these organizations. QHA is discussing the potential for direct funding from the State's Medicaid program and is also seeking a partnership agreement with Hawaii's DOH, which is considering the development of a bioterrorism communication network for Hawaii. Under this arrangement, QHA would provide the necessary infrastructure in exchange for HIE network usage fees paid by the DOH.

Challenges and Lessons Learned

Similar to the experience of other HIE projects, QHA is concerned about physician and hospital participation in the HIE network and general resistance to HIE implementation. Providers are hesitant to share clinical data on a real-time basis because of concerns around competition and quality. In particular, these concerns center around comparisons of patient outcomes without adequate risk adjustment or measuring quality based on non-representative patient outcomes. To counter this, QHA is working very closely with individual providers, and offering direct support to help them understand the impact of HIE and the benefits that the HIE network will afford them individually as well as afford their patients.

QHA actively sought to develop a solution that removes the traditional cost barriers for individual physicians. Oftentimes, physicians argue that EHRs are too expensive and thus unaffordable. QHA worked closely with a single vendor to substantially reduce the price and remove prohibitive costs from the equation for physicians who choose

The grant funds sought from the public and private organizations will support start-up costs, but subscriber fees will be viewed as the major revenue source for a sustainable health information network. QHA expects to add new participants each year to generate additional revenue. As more subscribers use the system and as more savings accrue to purchasers, QHA anticipates justifying increased user fees. Ultimately, for purchasers, a successful and sustainable HIE network will be dependent upon its ability to support the quality initiatives and reduce costs. It is hoped that the interaction and relationship of the HIE network components will perpetuate a sustainable life cycle.

To date, QHA stakeholders who plan to participate in the HIE network have indicated a willingness to support the requisite subscriber fee; however, the degree of commitment and amount of fees currently assigned varies. By the end of year two, QHA's goal is to have all subscription fees in place with participating stakeholders.

to participate. QHA identified a vendor partner that understood this approach and was able to base prices on volume, with an expectation that volume would significantly increase over the long term.

QHA has acknowledged the importance of engaging physicians early and often in the HIE discussions. In addition, employer engagement has been absolutely critical for the network's early progress. The interviewee stressed that employer buy-in will continue to propel QHA's efforts further and faster than other HIEs in the marketplace and that education was essential to engaging this stakeholder group. He stated that both the Federal government and other efforts across the country who want HIEs to be effective are "missing the most powerful force that could change the adoption rate—the employers." With health care costs rising, employers who pay to insure their employees must at some point become engaged. Nevertheless, QHA does recognize Hawaii's unique position where State law mandates employer health insurance. This factor forced the emphasis on cost and

quality—the two underlying principles upon which QHA built its model. The interviewee agreed that the incentive for employers may be greater in Ha-

wai than in other States where such laws do not exist.

Spotlight on State HIE Activity: Hawaii

- *Hawaii Life Science Council* is a non-profit organization focused on researching issues pertinent to RHIOs and serves as a resource for information, education, and guidance. They do not intend to develop or implement an HIE project at the present time.
- *Hawaiian Independent Physicians Association* is a group of physicians focusing on promoting adoption of EHRs.
- *Oahu HIE* is working to connect two federally funded community clinics and foster HIE.

Statewide Convener

QHA's vision is to create Statewide HIE. While there is no entity focused on Statewide collaboration today, the QHA would like to serve in this capacity and lead the collaboration amongst several other initiatives in Hawaii. QHA acknowledges the challenges that will exist in facilitating

communication and coordination across the islands' HIT activities given their own unique politics but QHA believes it can serve in this role. To date, however, QHA has focused more heavily on implementing its own initiative as opposed to coordinating or collaborating with HIE projects Statewide.



New York Telemedicine Demonstration Program

Dates of Note	<ul style="list-style-type: none"> 2005: Demonstration program established
Overall Program Objective	<ul style="list-style-type: none"> Evaluate the use and impact of HIT and remote monitoring technologies in the home care setting to improve health care quality and disease management and to identify costs, benefits, and efficiencies of utilizing technology in care delivery for home care patients
Engaged Stakeholders	<ul style="list-style-type: none"> State Government Select Home Health Agencies (Demonstration program contract awardees) Home Health Associations Physicians and other Home Care Providers Vendors (through home care agencies)
Target Population	<ul style="list-style-type: none"> Patient population served by home health agencies under the demonstration program
Technology/Infrastructure	<ul style="list-style-type: none"> Remote monitoring Interactive video technology Computerized physician order entry (CPOE) EHRs
Funding	<ul style="list-style-type: none"> State Appropriations—\$7 million
Timing	<ul style="list-style-type: none"> RFAs issued in 2004, awards announced in 2005; two-year HIT contracts began January 2006; additional RFA issued in January 2006
Unique Program and State Features	<ul style="list-style-type: none"> Department of Health is overseeing demonstration programs Significant State funding Emphasis on home health and long-term care population New York allocated \$1 billion in capital funding to promote health care system improvements including HIT

Overview

The New York State Department of Health's (DOH) Telemedicine Demonstration Program was established in 2005. The overall goals were to generate additional knowledge and experience; collect information relating to the use of telemedicine technologies in the home care setting; and evaluate the appropriateness of incorporating these technologies into the Medicaid Program and the appropriateness of Medicaid reimbursement for these technologies. Home care and LTC patients are frequently not included in HIE projects, but often have needs that can be well-addressed through the use of HIT and data exchange. These patients are often disassociated from a care regimen and

frequently do not interact regularly with their providers. This can put these patients at increased risk for poor compliance or negative clinical outcomes as a result of inconsistent care. New York's Telemedicine Demonstration Program is working to address these challenges and striving to improve outreach and clinical outcomes to the State's home care patients.

Administered by New York State's DOH, the demonstration program will enable the Department to identify new technologies to improve quality of care and disease management for home care patients. By supporting the exchange of health information between providers and home care agencies and

connecting providers to patients who are in different locations, telemedicine and HIT may be able to provide a variety of benefits, including improved access to care, improved clinical outcomes, provision of more effective care, and increased patient compliance. In addition to these quality goals, the

demonstration program will examine the costs, benefits, and efficiencies of a range of technologies and assess whether Medicaid should reimburse for the use of HIT and remote monitoring technologies in the delivery of care for home care patients.

Planning and Implementation

Planning With nearly 350,000 homebound patients⁶ treated through the State's 192 certified home health agencies⁷ and 900 licensed home care service agencies,⁸ New York has a prominent home health segment. Notably, the program was initially conceived of and driven by a set of home care agencies and associations. Through their close working relationship and outreach with the State and the DOH, collaboration and project planning began. In the initial planning stages, DOH met with and visited home care agencies and other health care providers both in and outside of New York who had incorporated HIT and monitoring technologies in their service delivery. Additionally, DOH reached out to vendors to understand the market and various technology offerings and consider the applicability of specific technologies to the home care setting.

In July 2005, the Telemedicine Demonstration Program awarded \$4 million to select home care agencies across the State through a competitive request for applications (RFA) process. Out of a total of 52 applications received, the State awarded 30, two-year contracts that went into effect in January 2006. In addition, a second RFA for an additional \$3 million was released that same month. Applications for the second RFA are due to the DOH March 31, 2006. Although the demonstration programs will initially target a select set of home care agencies through the contract awards process, program leaders hope the demonstration will eventually provide evidence that supports the use of these technologies to home care agencies and home care patients Statewide.

⁶ http://www.nyshcp.org/about_home_care_prnt.shtml

⁷ Certified Home Health Agencies are certified to provide home health care services for Medicare and Medicaid patients.

⁸ These agencies are not licensed for Medicare and Medicaid and do not provide the full array of home care services that are offered by Certified Home Health Agencies.

Timeline

January 2005

DOH releases RFA for Telemedicine Demonstration Program

April 2005

Applications for the RFA due to DOH

July 2005

Governor Pataki publicly announces the State's contribution of \$4 million to the New York Telemedicine Program

January 2006

Two-year contracts begin for 30 home care agencies

January 2006

A second RFA for \$3 million is released for the Telemedicine Demonstration Program

March 2006

Applications for the second RFA are due to DOH

Many of the programs funded through the RFA will focus on chronic health conditions, such as congestive heart failure (CHF), diabetes, and chronic obstructive pulmonary disease, however, the technologies used for these conditions will be quite varied. The RFA provided broad inclusion criteria for the technology in serving the home care population. Proposals eligible for funding could include projects that facilitate the provision of therapies by licensed professionals through the use of technology; projects that enhance collaboration and communication among health care staff; and projects that contribute to improving the quality of care and disease management through the use of telemedicine technology. Many of the submitted proposals focused on transmission of vital signs, wound care, telemedicine, and physician ordering and will be

supported through web portals, interactive video

technology, CPOE, and EHRs.

Implementation Initial and subsequent contract implementation will occur in 2006 and 2007. DOH anticipates that the demonstration program will:

- Offer insight into the benefits of HIT and remote monitoring technology;
- Reveal best practices in using this technology to serve the home care population;
- Demonstrate ways in which the technology can improve collaboration and communication across the team of care providers serving the home care population; and
- Showcase the value of and potential for future reimbursement for these technologies under the New York Medicaid program.

As part of the application and funding selection, home care agencies were required to submit plans

on how they would evaluate their projects. Outcomes that will be measured include quality of care; appropriateness of use of the technology in the home care setting; whether access to home care was improved; whether clinical outcomes were improved; and how the cost of home care service delivery was affected in terms of efficiency, effectiveness, and appropriateness of use under the Medicaid program. Evaluations of the funded programs are due annually to the DOH. Based on these evaluations, DOH will issue an annual report to the Governor and the legislature on the funded programs and the appropriateness of incorporating the use of telemedicine technologies into the Medicaid program.

Financing and Sustainability

The New York State legislature allocated \$4 million to initiate the Telemedicine Demonstration Program in January 2005 as part of the State budget and later allocated another \$3 million as part of the 2006 budget. Various New York home care associations and select home care agencies were integrally involved in promoting legislation that enabled the DOH to embark on this demonstration. As a result, Governor Pataki set aside funds for the RFAs. Awards are capped at \$150,000 for the two-year contracts and all home care agencies with integrated telemedicine systems or agencies that wished to pursue, expand, upgrade, enhance, or otherwise modify their technologies were eligible to apply.

Currently, there is not a long-term financing strategy for the Telemedicine Demonstration Program or for future expansion of the program. One of the program's goals is to evaluate the benefit of tested technologies to determine if Medicaid should ultimately reimburse for these services. Program officials hope the demonstration program will spur

“Home care agencies are a special entity because it makes sense for them to be sharing information with physicians and hospitals. The problems start when physicians, hospital, and payers view the information as proprietary and don't see it [sharing data] contributing to their success.”

additional interest in telemedicine among home care agencies and most important, that the State will conclude that it will be cost-effective for Medicaid to reimburse for HIT and remote monitoring. Such reimbursement would enable long-term sustainability of HIT and remote monitoring programs in the State. It would also encourage smaller, private home care agencies to make capital investments that could significantly enhance the quality of care and decrease health care costs for this population.

Challenges and Lessons Learned

New York has a history of participation in a broad array of demonstration and waiver programs, therefore the DOH anticipated a number of challenges when implementing the telemedicine demonstration program. In addition to barriers associated with funding, privacy, and security, DOH continues to face an additional logistical challenge of coordinating the 30 home care agencies funded through the initial RFA and an even greater number once the second RFAs are awarded. The DOH also faces technological barriers as home care agencies tend to be less technologically advanced than other health care stakeholders.

DOH also understands that provider resistance is often a major barrier in successfully incorporating and adopting HIT. For example, home care agencies that have incorporated telemedicine or remote monitoring technology indicated to DOH that many providers are reluctant to have information electronically transmitted to them; are hesitant to reference information electronically; and have concerns about research tools and the quality of the decision support information supported by the technology. To proactively address and manage these challenges, DOH required that applicants outline how they will:

- Enlist physician support;
- Use other marketing strategies in their outreach to providers; and
- Enlist patient participation.

In general, DOH's application requirements were intended to both anticipate and assuage provider resistance to the program upon implementation.

Despite the challenges, New York has learned valuable lessons in launching the demonstration program. Program officials acknowledged the importance of looking at existing telemedicine projects to become familiar with their utilization and

uptake rates, and to understand the specific vendor offerings and types of technology in use. Additionally, officials stressed the importance of engaging multiple stakeholders and showcasing the shared positive benefits for quality and cost of care.

Home care agencies, associations, and the New York State DOH have been the primary stakeholders in this program. Additionally, vendors working directly with home care agency grantees, rather than DOH directly could potentially take on a greater role in the future if certain technologies are deemed beneficial by the State in serving the home care population.

The interviewee indicated that in particular, the State's involvement and broad support was instrumental in launching the program and has been beneficial in helping to manage program challenges. In general, the State of New York has demonstrated strong support for HIT and HIE and is supporting the Health Care Efficiency and Affordability Law for New Yorkers (HEAL-NY) and the Federal-State Health Reform Partnership for HIT (F-SHRP). These programs will focus more broadly on HIT efforts across the State, but are not yet coordinating information or collaborating directly with the Telemedicine Demonstration Program. Additionally, although these programs will reach distinct populations, there is clear overlap and the interviewee shared that a number of home care agencies funded under the Telemedicine Demonstration Program also applied for funding from F-SHRP. In light of the long-term goals for HIE, i.e., authorized access to real-time health information where and when it is needed, it would bring value to the multiple HIT and HIE programs in New York to develop methods for effectively communicating, collaborating, and exchanging information with other HIE projects across the State.

Spotlight on State HIE Activity: New York

- *HEAL-NY* will provide \$1 billion in capital grant funding over the next four years to help facilitate the transition to a new and improved health care system in New York State. These funds will support facility improvements, reconfiguration and consolidation, information technology enhancements, and other projects to enhance the efficiency of facility operations.
- *F-SHRP* plans to reinvest \$1.5 billion of Federal fund savings to make “long-term systemic improvements to the health care delivery system in New York.” Although the details are yet to be finalized, eRx, EHRs, and RHIOs are contemplated within this effort.
- *Primary Care Information Project Taskforce* plans to use HIT to improve the health of New York City residents by coordinating the DOH and Mental Hygiene activities and promote the use of EHRs, HIE, and biosurveillance.
- *Taconic Health Information Network and Community* will add a web portal to the existing community-wide electronic data exchange which will allow for use of the current electronic messaging system and a migration to a full EHR.
- *Visiting Nurse Service of New York* increased its efficiency and improved patient care with an EHR that streamlined workflow processes and reduced paperwork.

Statewide Convener

New York supports a number of HIT and HIE projects across the State, yet to date, no single entity has formally served in a collaborating or coordinating role. The interviewee noted that organizations such as the Health Plan Association are working to coordinate information flow; however, this is not happening Statewide.

In spring 2005, New York’s DOH launched the HIT Working Group, comprised of representatives from the DOH and other State agencies including the Governor’s office to promote Statewide collaboration and coordination across the State’s various HIE activities; effectively respond to Federal HIT activities; and ensure that New York is at the forefront of these efforts. The workgroup is charged with the following functions:

- **Communication:** Assure that the various State agencies and departments are informed about their respective HIT activities; serve as a focal point for communication with the Federal government and with various New York communities, providers, and payers; and interact with the general public on the benefits of HIT projects;
- **Coordination and Knowledge Center:** Serve as a central source of information on HIT and relevant issues including regulatory, financing, legal, and technology; and
- **Policy Advice:** Informally advise State entities involved in HIT related policy issues.



North Carolina Healthcare Information and Communications Alliance (NCHICA) Healthcare Quality Initiative (HQI)

Dates of Note	<ul style="list-style-type: none"> 1994: NCHICA established 2003: HQI launched
Overall Program Objective	<ul style="list-style-type: none"> Enable access to the highest quality, safest, and most efficient health system by providing secure exchange of clinical information in an interconnected community of stakeholders
Engaged Stakeholders	<ul style="list-style-type: none"> State Government Health Plans Clearinghouses Physicians/Physician Groups Physician Associations Hospitals Research Organizations Vendors Lab Providers Employers Consumers
Target Population	<ul style="list-style-type: none"> Statewide
Technology/Infrastructure	<ul style="list-style-type: none"> eRx Electronic order entry and results reporting EHR Initial project – point of care medication management
Funding	<ul style="list-style-type: none"> Federal—\$1.5 million Membership fees and in-kind support Private Sector—Industry/Large employers
Timing	<ul style="list-style-type: none"> Planning for HQI began in 2003; implementation and data flow for Phase I-Medication Management component expected 2006
Unique Program Features	<ul style="list-style-type: none"> Long-standing relationship and credibility among health care stakeholders across the State Significant involvement of large employers ONC contract awardee for NHIN Prototype with medications management as use case (IBM is primary contractor) Establishment of Consumer Council

Overview

The North Carolina Healthcare Information and Communications Alliance, Inc. (NCHICA) was established in 1994 pursuant to an Executive Order issued by Governor Jim Hunt to improve health care by accelerating the adoption of HIT. As such, NCHICA sponsors educational programs and demonstration projects to facilitate the

development of a Statewide health care information network that will incorporate open architecture and interoperable systems to improve the safety, quality, effectiveness, and efficiency of health care. Operating as a 501(c)(3), NCHICA has built trust and encouraged collaboration among all sectors of

the health care industry including the State and Federal government.

NCHICA's history began prior to 1994. Home to innovative hubs such as Research Triangle Park, North Carolina has a history of cultivating innovations. During his four-year term tenure, Governor Hunt helped foster the focus on technology by encouraging the placement and utilization of extensive fiber optic networks in the State, and by creating workgroups to determine how best to utilize the ensuing bandwidth. As a result of these working groups, North Carolina began exploring the use of the bandwidth for telemedicine and interactive video in the early 1990s—long before usage of these technologies was common place.

NCHICA maintains a strong relationship with the State and benefits from extensive State government representation and support. Many governmental offices, including the Governor's office, the Division for Medical Assistance (Medicaid), and the Division of Public Health are NCHICA participants and hold positions within the organization. NCHICA is involved with a Medicaid program that serves disabled, chronically ill patients. This program, led by the State Division of Medical Assistance, has expanded to serve 700,000 of the State's 1.2 million Medicaid recipients and is now transitioning into "data environment" that utilizes more universal standards for messaging and communications. NCHICA is also working with the Medicaid program to submit a joint application to the North Carolina Health and Wellness Trust Fund to adapt and promote disease registry technology that will be used in primary care settings to treat patients with obesity, CHF, and diabetes.

Throughout its long history, NCHICA has been instrumental in supporting and spearheading State-wide HIT projects. One such example includes the

Planning and Implementation

Planning NCHICA's Board of directors embraced the goals and objectives of the HQI in 2003 and initial implementation is expected in 2006.

HQI will be implemented in the following order:

- Phase I
 - » *Medication management* will provide clinicians with patients' medication history

Timeline

2003

NCHICA Board articulates goal to make medication history information available to providers and care managers

2005

IBM, CIGNA, and NCHICA discuss efforts to improve care with initial thrust in Triangle area with a goal of expansion Statewide

2005

NCHICA receives two awards for NHIN prototypes

2006

Implementation of Medication Management Initiative, Phase I of HQI

immunization project,⁹ which combined children's immunization records from multiple sources. The project ultimately captured immunization data on more than two million children in North Carolina; and standardized and electronically collected clinical data from EDs across the State for best practice development, community assessment, and public health surveillance.

More recently, in response to high health care costs, high pharmaceutical utilization, increased recognition of the benefits of information sharing, and several successful efforts by large employers in the State to improve care, NCHICA launched the Healthcare Quality Initiative (HQI). HQI will be launched in a three-phased approach and aims to improve the quality, safety, and efficiency of health care in North Carolina through the use of secure and standards-based information technology and information exchange.

⁹ Provider Access Immunization Registry Secure (PAIRS)

"What they [State leadership] bring to the table is some validation and credibility of NCHICA—having the Governor and Secretary talk about NCHICA makes a big difference when you are trying to get something done."

at the point of care and will integrate this information with automated refill, formulary and benefits information, and eRx.

- Phase II
 - » *Lab and radiology reporting* will support electronic lab and radiology ordering and results at the points of care.
- Phase III
 - » *EHR adoption* focuses on supporting broader adoption of EHRs.

NCHICA's stakeholders recognized that more information at the point of care can lead to higher quality and more cost-effective care. However, it was through discussions with physicians and the recognition of the "low hanging fruit" that prioritized HQI's phases and the initial focus on medication management. The interviewee noted that some of the most poignant Statements came from physicians who said "If I only knew what other medications [patients] were on, that would be a great step in understanding what problems or drugs I need to avoid." Emphasis on the refill process and access to formulary and benefit information, including pre-authorizations, were also viewed as major time savers for physicians although NCHICA realizes that for physicians, the economic benefits of eRx are not totally proven or clear.

NCHICA articulated the following programmatic goals, which coincide with the three-phased approach described above. They have not yet developed an action plan for many of these goals, but see them as essential for their long-term strategy of supporting HIE across the State.

1. Improve medication administration, coordination, and safety by:
 - a. Making standards-based medication history/prescription information available;
 - b. Facilitating automated refill processing;
 - c. Assisting in widespread access to patient level formulary information; and
- d. Accelerating adoption of eRx, under appropriate procedural authority, to providers of care and those directly involved in care management.
2. Improve quality and efficiency of diagnostic procedures through point-of-care lab and radiology ordering and results;
3. Enable improvements to provider office efficiency by incenting the adoption of automated tools for practice management and clinical information exchange;
4. Implement and create (as necessary) a new financing mechanism linked to process redesign to support pay-for-performance programs;
5. Investigate potential avenues within the Stark laws to permit organizations to financially support clinical information system adoption in providers' offices when supporting broad interoperability solutions for the State;
6. Implement and/or develop infrastructure to manage clinical information exchange capabilities throughout the State, leveraging the Nationwide Health Information Network (NHIN) prototype activities; and
7. Offer support to providers in North Carolina to accelerate adoption of standards-based, EHR solutions with an emphasis on the policy changes and community acceptance elements necessary for success.

The medication management component will initially begin in the Triangle region¹⁰ and target nearly 20% of the State's population. NCHICA hopes to roll out this phase of HQI Statewide within two years. They believe that once the capacity is established and most of the major payers and pharmacies are participating, "there is no limit to participation."

¹⁰ The Triangle region – also known as Research Triangle Park – represents Raleigh, Durham, and Chapel Hill.

Implementation Components of this implementation will include:

1. Delivery of patient's medication history (phase I), lab results, radiology reports, and allergy data (phase II) in an electronic format to physicians at the point of care;
2. Integration of patient's medication history with systems for electronic refill and prescribing;
3. Demonstrating the value of using technology partnerships that employ standards-based, open-source, and scalable architecture; forming close collaborations with multiple

- stakeholders, and establishing a specific strategies to enhance clinical adoption; and
4. Proving that the privacy and security issues for such a service are manageable.

NCHICA credits the enthusiasm surrounding HQI to support from its stakeholders, which represent a subset of NCHICA's membership. HQI was not driven by one single stakeholder group, but rather enjoyed broad support. The project was strongly backed by NCHICA's Board and all of NCHICA's active workgroups contributed their expertise. Physicians, including those on NCHICA's Board, members of the North Carolina Medical Society, and Carolina's Center for Medical Excellence (QIO), as well as several independent practice associations have also played a central role in the planning and promotion of HQI. Private sector representatives and vendors have also been very active in NCHICA and HQI.

IBM was particularly supportive of HQI because of their significant employee population that lives in the Triangle area—over 40,000 covered lives. CIGNA, IBM's health plan carrier, also committed to support the initiative. Notably, NCHICA/HQI has become one of the use cases (HIE scenarios to demonstrate the value of HIT) for IBM's contract with ONC under the NHIN prototype architecture award. NCHICA also has been requested by the Governors Office to respond to the Privacy and Security RFP from ONC/AHRQ through RTI International and NGA and lead a collaborative effort to understand what State laws and business customs may inhibit the exchange of health information

“Efforts under way around the State will be key to building those connected communities locally. If we can build the proper bridges, NCHICA can be the collaborating, facilitating entity that can bring these separate entities together to build Statewide connectivity in a standards-based way.”

within and between States. This activity is expected to begin in the spring of 2006 and extend into mid-2007.

As NCHICA moves forward with HQI, it will continue to monitor certification and standards activities at the national level (e.g., Certification Commission for Healthcare Information Technology—CCHIT) to determine how to tailor and direct its own HIT efforts, particularly in the context of EHR benefits, specific benefits and functionality for physicians, and upcoming pay-for-performance and performance measurement activities.

As an incremental step towards EHR adoption, NCHICA is also hosting a May 2006 workshop to examine a simple, low-cost disease registry that will track patient populations and help providers manage patient care. As for future HQI phases, NCHICA expects to take a similar approach—one that is inclusive of all stakeholders and identifies the value for its members, yet indicated they are still in the early planning stages.

Financing and Sustainability

NCHICA's focus on identifying and articulating the technology value and business case for its members has been vital to its sustainability and continuing community support. Likewise, its membership dues, in-kind member donations, and external funding sources are also essential to support the speed and breadth of NCHICA's activities. Most recently, NCHICA, in partnership with IBM, obtained \$1.5 million in funding and additional in-kind support for HQI as one of the awardees for the NHIN prototypes. NCHICA credits this award to its continuing efforts to educate and recruit employers

and health plans into the project. NCHICA acknowledges that this NHIN award accelerated their activity, but indicated HQI would still be a priority even without external funding.

NCHICA and HQI's broad base of stakeholders has been particularly beneficial in advancing the project. Clinicians are enthusiastic about the potential to reduce the length of a patient encounter by 10-40%,¹¹ improve patient safety, and automate medication refills. Employers, payers, and pharmacies

¹¹ NCHICA's analysis

see HIT as an opportunity for cost savings from increased use of generics, fewer outbound calls to physicians, and automated prescription refills. NCHICA also sees HQI as way for many of its member organizations to better understand technology trends and anticipate upcoming product development needs.

Moving forward, HQI will be seeking participation of other employers and payers Statewide. To help

ensure long-term self-sufficiency for HQI, NCHICA is developing a strong business case for physicians' offices, payers, employers, and ancillary providers to facilitate investment and support of these quality and cost driven activities. Nonetheless, the interviewee Stated that it is currently unclear how much external funding will be necessary in both the short and long term to sustain the HQI.

Challenges and Lessons Learned

As an organization with a long-standing history and far reaching membership, one of NCHICA's foremost priorities and challenges is to balance its members' various interests. In recent projects, including HQI, NCHICA acknowledges a host of challenges including agreements among multiple business partners (e.g., health plans, PBMs, providers, and consumers); access to government sources of data (e.g., Medicare and Medicaid); development of and compliance with technical standards; and identification of an effective sustainable business case.

“You need to have physician champions. When you have a room full of technical folks you need to have a physician present. They are a canary—if they twist and get nervous, then you know something might be a problem.”

As HQI overcomes these barriers, it continues to take away key lessons from each project. Some of these lessons are learning to choose projects with clear benefits, celebrate successes, find clinical champions and enlist CEO-level champions, and recognize that the technology may be the easier part, and the business or policy issues may be the real battle. NCHICA also acknowledges the importance and benefit of the State's involvement, a point the interviewee was clear to emphasize. For example, although State agencies have long been involved in NCHICA, many staff members attend NCHICA meetings to learn techniques and methods from the private sector and determine if those same methods can be applied at a State level. The State involvement has also helped to validate NCHICA and increase its credibility to members and other stakeholders. The interviewee acknowledged that despite broad stakeholder support,

some activities to date have been met with privacy and security concerns, often typical of HIT projects. NCHICA has both a privacy and a security workgroup that focuses on these ongoing issues.

Through a variety of strategies, HQI has reached out to typically under-represented and often challenging to reach stakeholders including consumers, representatives from the mental health sector, small to medium-sized physician practices, laboratories, and pharmacy boards. For example, NCHICA is establishing a Consumer Advisory Council to provide input into the project. Additionally, representatives from two psychiatric and psychological societies (part of NCHICA's membership), and two independent practice associations, that represent small and medium-sized physician practices, will be providing input. To date, NCHICA has not engaged the long-term care and home health community but may do so in the future.

NCHICA's credits much of its success to its collaborative effort, noting that in addition to leadership from the State, it is crucial to have leadership from employers, industry, professional associations, academic health centers, hospitals, medical groups, and specialty societies. NCHICA also credits some of its support to its close ties to the physician community. NCHICA has engaged key physicians who understand the relationship between quality and technology and incorporated these physicians into a leadership team that spreads awareness of the project and garners support for the program. NCHICA encourages States to look for this leadership – particularly within the physician community – and also to be cognizant of working in a standards-based manner that is compliant with the Health Insurance Portability and Accountability Act of 1996 (HIPAA) to assuage any privacy concerns.

NCHICA's alignment with State and private sector priorities has also helped it reduce costs and meet budgetary and quality concerns through the use of HIT. The interviewee noted that by keeping the

health and safety of individuals as its core objective and offering benefits to all stakeholders, NCHICA has built a successful, collaborative HIT and HIE environment in North Carolina.

Spotlight on State HIE Activity: North Carolina

- *Western North Carolina Regional Data Link Project* is a group of institutions in Western North Carolina focused on collecting clinical information from patients and customizing care management services for each patient, including education, risk-reduction programs, and medication assistance.
- *North Carolina Immunization Registry (NCHICA Initiative)* created a tracking mechanism for the Universal Childhood Vaccine Distribution Program.
- *Provider Access to Immunization Registry Securely (PAiRS) (NCHICA Initiative)* consolidated immunization data from three independent databases and allowed health care providers across North Carolina to securely access this data. The project operated from 1998 until July 2005 when it was replaced with a State-of-the-art immunization registry built by the State of Wisconsin and underwritten by funding from CMS.

Statewide Convener

NCHICA serves as a facilitator, convener, and collaborator with other HIE projects in the State, but has no regulatory, supervisory, or budgetary authority over any other organization. NCHICA supports, educates, and assists other projects to promote HIE and technology adoption, including helping the projects understand appropriate standards, common roadblocks, and keys to success. Although NCHICA works to ensure that the various State activities are collaborating and coordinating to the degree it makes sense to do so, NCHICA has

not historically offered unsolicited advice. NCHICA typically waits for other projects to reach out for assistance in order to remain “above suspicion or reproach.” Through this approach, NCHICA has engendered a high degree of trust and credibility with its membership and across the State. It has also been successful in bringing together varying viewpoints, resources, and knowledge to further advance the adoption of information technology and information exchange across the State.



Rhode Island Quality Institute (RIQI) Health Information Exchange Initiative

Dates of Note	<ul style="list-style-type: none"> ▪ 2002: RIQI established ▪ 2003: Initial HIE Initiative planning ▪ 2004: HIE Initiative launched
Overall Program Objective	<ul style="list-style-type: none"> ▪ Enable and reward delivery of high quality, safe, cost-effective care on a community-wide basis by building an information infrastructure that supports access to patient information and current medical knowledge and data.
Engaged Stakeholders	<ul style="list-style-type: none"> ▪ State Government including Medicaid ▪ State QIO ▪ Hospitals ▪ Physicians and other health care providers ▪ Provider Associations ▪ Payers ▪ Consumers ▪ Businesses ▪ Academic Institutions ▪ Employers ▪ Pharmacies
Target Population	<ul style="list-style-type: none"> ▪ Statewide
Technology/Infrastructure	<ul style="list-style-type: none"> ▪ MPI ▪ EHR ▪ Initial project—exchange outpatient lab data and medication history
Funding	<ul style="list-style-type: none"> ▪ Federal—\$5 million over five years ▪ Private sector—Foundations, \$296,000 ▪ Stakeholder contributions—\$50,000
Timing	<ul style="list-style-type: none"> ▪ Project planning under way; workgroups formed, governance established, and technology vendor being selected. Initial lab and medication data exchange expected late 2006/early 2007.
Unique Program and State Features	<ul style="list-style-type: none"> ▪ Heavy involvement of Statewide private and public sector health care leaders ▪ Physician-based entity selected single EHR vendor to support HIE Initiative ▪ Rhode Island Department of Health (HEALTH) serves as AHRQ State-Regional Demonstration Grant recipient ▪ HEALTH contracted with State QIO to engage physicians ▪ Consumer outreach through consumer advisory committee and a contract with public relations consultants

Overview

In 2004, Rhode Island established the Rhode Island Quality Institute (RIQI), a non-profit coalition of leading health care stakeholders across the State

including providers, payers, government, consumers, business, and academia. RIQI was established to encourage science-based, appropriate, and

cost-effective health care decision making and to improve health care quality, safety, and efficiency in Rhode Island. Rhode Island's State government has and continues to play a central role in the establishment and ongoing support of RIQI. A variety of State officials including the Secretariat of Health and Human Services, the Director of Health, the Rhode Island Health Insurance Commissioner, the Medicaid Director, and the Lieutenant Governor continue to be integrally involved in RIQI and are part of the organization's senior leadership. The Governor also provides significant leadership. This fall, the Governor announced his five point health care agenda which includes a focus on "Anytime, Anywhere Health Information" as one of the points, and relies on the partnership between HEALTH and RIQI to support the necessary work.

Specifically, RIQI is working to:

- Leverage the State's unique characteristics (e.g., small size, governmental accessibility) to demonstrate how the health care system can be improved through collaborative innovation;
- Make Rhode Island the safest place in the nation to receive health care;
- Foster connectivity between/among the health care team (including the patient);
- Increase accuracy, responsiveness, and effectiveness in health care by using technology to standardize, streamline, and speed up the retrieval and delivery of patient data Statewide;
- Help the health care team consistently deliver care that is based on best practices; and
- Create a system that inspires and rewards improved professional performance.

To meet these goals, RIQI is supporting initiatives that will foster a useful and usable health information system that will give providers and patients access to appropriate information where and when it is needed. This will ultimately support the analysis of population health information to enable quality improvement, evaluate the effects of system changes, enable research, and inform State poli-

Planning and Implementation

Planning In late 2003, expanding on the success of the SureScripts initiative, RIQI and HEALTH began to work on understanding the HIT landscape and determining how to best expand HIE efforts

Timeline

2004

RIQI/HEALTH develop concept and model for HIE Initiative; submit AHRQ contract application and receive grant award

2005

Technology infrastructure planning and straw man development under way; workgroups established; data prioritization plan developed; Governor announces HIT as one of five major health care agenda items

2006

Consumer and provider outreach ongoing; vendor selection by April 2006

2007

Initial data exchange expected

cymaking. To date, RIQI has focused on the SureScripts Electronic Prescribing System^{TM12} – a collaborative effort between independent and chain pharmacies across the nation – to implement Statewide electronic connectivity between all retail pharmacies and all prescribers in Rhode Island. RIQI has also launched a Statewide Intensive Care Unit (ICU) Collaborative to decrease mortality and complications in the ICU – a project in which every hospital in Rhode Island is participating.

Building on its activities and stakeholder goals and priorities, RIQI is providing the governance structure for the Rhode Island Health Information Exchange Initiative (HIE Initiative) – an effort to promote appropriate and timely access to health information data across the State. RIQI also spawned Electronic Health Records of Rhode Island (EHR of RI), a company formed by some of the largest physician organizations in the State, that serves as a reseller of EHRs and actively promotes the adoption and use of EHRs by all physicians across the State.

¹² <http://www.surescripts.com/>

across the State. Through these efforts, RIQI learned that many early HIT efforts had failed because they were too specific in nature, did not enlist a broad spectrum of key stakeholders, did

not adequately address physician adoption issues associated with the effort, and did not understand financing and sustainability challenges. As their learning progressed, RIQI and HEALTH began to view HIT as a critical enabler to the improvement of health care quality, safety, and value, and recognized the benefits of data exchange across the State.

Cognizant of the many pitfalls and determined to avoid them, RIQI worked closely with HEALTH to develop an HIE model and to think more broadly about using HIT to improve the quality of care. The initial concept, which was developed in part with a consulting firm¹³ and submitted as part of an AHRQ planning grant, was to target and “wire” a single Rhode Island community. The interviewees noted that other Rhode Island communities promptly took notice and had a desire to participate in the project. Broad community interest in the HIE model spread and quickly the concept transitioned from a community-wide approach to a Statewide effort.

With luck on Rhode Island’s side, AHRQ announced the State and Regional HIE Demonstration Projects shortly after RIQI developed its initial HIE model. Based on its understanding of Rhode Island’s needs and its work to date, HEALTH, with significant assistance from RIQI, felt confident that it could complete and submit AHRQ’s contract application. In late 2004, HEALTH was the recipient of a five-year, \$5 million AHRQ State and Regional HIE implementation contract to support Rhode Island’s HIE Initiative.

With the HIE Initiative as a centerpiece, RIQI intends “to demonstrate that appropriate, science-based, cost-effective care can be delivered consistently across an entire medical community, resulting in better quality and lower costs.” Additionally, the goal is to transform the quality of Rhode Island’s health care delivery system through local governance by implementing clinical information systems and process improvements across physician communities; by connecting information from physicians, hospitals, labs, imaging systems, and other community providers; and by encouraging adoption of best practice innovations.

¹³ The relationship with the consulting firm ended after RIQI developed its initial HIE model.

“A community entity that has balance between the government and private sectors is probably the best of both worlds from a protection standpoint and from a consumer point of view to ensure that the right checks and balances are put in place.”

To meet these goals, Rhode Island plans to implement a MPI that will help identify unique patient data from various electronic sources and sites of care to be viewed in a uniform manner by providers. The ability to access comprehensive patient data will be made available to all providers regardless of whether or not they have an EHR. Initially, access to the data will be provided through a web-based portal. It is anticipated that the system will be able to interface with an EHR so that the aggregated data can be incorporated into a physician’s EHR. The HIE Initiative will also provide decision support and allow for data analysis for public health surveillance, evaluation, and research. Vendor responses to the Request for Proposals (RFP) are currently being submitted and HEALTH intends to select a MPI vendor by May 2006. RIQI also intends to promote the use of financial incentives for physicians to encourage broad adoption and utilization of the technology.

RIQI and HEALTH are using the AHRQ contract to directly support the HIE Initiative and its six key functions and objectives:

1. Enable consumers to share their health information by having them decide when and with whom they want to access and share it.
2. Use MPI functions to help uniquely identify an individual and locate where a patient’s health information is stored.
3. Present data from a variety of sources in an integrated, patient-centered manner using a common user interface, such as a portal or local platform.
4. Integrate data into EHR applications and support the exchange of this data with others, as permitted.
5. Provide decision support capability.
6. Create the ability to aggregate and utilize data for public health purposes, such as population-

based analysis, quality improvement, evaluation, biosurveillance, and research.

Shortly after the AHRQ contract was received, but when the HIE Initiative was still in its early planning stages, program leadership sought stakeholder input to: 1) formalize the planning and development process; 2) better understand how the initiative could meet its objective, and; 3) ensure broad stakeholder participation. Program leadership held public meetings that generated a high level of interest as well as a “healthy level of skepticism.” Next, HIE governance was established, which included the development of five workgroups. These workgroups were designed to support the Initiative and provide input into appropriate starting points and direction for the HIE Initiatives activities. The workgroups focused on:

- Technical solutions;
- Data sharing partners;
- Engaging consumers;
- Engaging providers; and
- Legal and policy issues.

A formal steering committee within RIQI, the RIQI HIE Steering Committee, was also established to oversee the AHRQ contract, serve as the decision making body for the project, and promote Statewide coordination.

In 2004, as part of RIQI’s Clinical IT Leadership Committee, RIQI brought together leaders from competing physician groups across the State to discuss key features and functions of an EHR that would support the HIE Initiative and support

adoption of EHR technology. The overarching goals of this collaboration were to reduce variation in the selected technology, help improve rates of adoption, simplify connectivity to the HIE, and ultimately improve quality of care. As a result of their newlyformed working relationship, shared vision, and a determined need, the physicians formed “EHR of RI”, a for-profit company representing more than 50% of Rhode Island physicians, to support group purchasing and technology installation and maintenance for participating physicians.

After working together for nearly eight months and reaching an agreement on core EHR features, the physicians selected a single EHR vendor.¹⁴ Notably, they used the company’s purchasing power to provide a significant price reduction for the chosen technology. EHR of RI’s decision to commit to a single vendor was not intended to restrict providers’ choices but rather to reduce the cost of adoption and the fragmentation that often results from multiple vendors.

EHR of RI is not directly related to the HIE Initiative, although there is significant overlap of stakeholders and the company’s activities are designed to integrate with the HIE Initiative. To date, there has been a great deal of excitement and publicity surrounding the company’s formation. Recently, however, some questions have been raised about the relationship between RIQI and EHR of RI, and about how RIQI will support EHR of RI efforts but in a manner that will not be exclusionary of others.

¹⁴ The selected vendor has not yet been publicly announced.

Implementation After several months of collaborative discussions, a decision was made to build, prioritize, and roll out the HIT initiatives in specific components, (e.g., MPI, EHR, incentives) with a significant emphasis on Statewide health data exchange. With insight and direction from its workgroups, the HIE Initiative determined it would be most efficient to develop a data prioritization plan based on the feasibility and desirability of data exchange that could be supported in the near term. Consequently, outpatient lab data was prioritized to be the initial data exchanged; followed by medication data; reports data which will include ED and

“We went from thinking very big and broad—i.e., create a MPI and connect data sharing partners—to focusing on the deep and narrow, but when we started really drilling down, it was not that simple.”

hospital discharge, lab, outpatient reports; and then administrative data.

Based on additional discussions with providers, program leadership is currently contemplating how to roll out the initial data exchange. Program officials initially planned to focus on making lab data

from three data-sharing partners available to a subset of providers affiliated with the primary data partners. Officials believed this approach would make retrieving data more convenient for network physicians by consolidating patient information into one location. However, after discussions with the physician advisory group (a group convened by the State's QIO) officials realized that laboratory point-to-point connections are being created in many hospitals giving physicians greater access to this information. Hence, laboratory data exchange within a network may not prove to be as valuable or have as many benefits as originally expected. The interviewees acknowledged that physicians outside the established networks would potentially realize greater value to the laboratory data exchange because they are currently unable to access patient information when their patients are admitted to a network facility.

The HIE Initiative is continuously evaluating its implementation and data prioritization strategy. Program officials learned through dialogue with the physician advisory group that providers are particularly interested in access to medication history information. To meet this need, the HIE Initiative will be working with SureScripts on a new project to support access to medication history information. This effort may allow medication history data to be available through the HIE Initiative around the same time as laboratory data.

Development of a technical model was also a major priority for the HIE Initiative. Through the spring and summer of 2005, the technical solution workgroup conducted a gap analysis of the potential data-sharing partners, assessed the State's existing infrastructure to understand what could be leveraged on behalf of the HIE Initiative, defined the business process and technical requirements for developing a MPI, identified initial legal and policy issues that needed to be addressed, and developed recommendations for an HIE technical infrastructure. Based on this work, the committee put forth a technical "straw man" for a MPI linking decentralized clinical data categories and identifying a number of key attributes including:

- Equitably distribute costs of data exchange;
- Provide flexibility to enable both the small and large institutions to share data;

- Support scalability and adaptability;
- Provide a rapid response time; and
- Create an opportunity to build an infrastructure to maximally benefit public health.

Long-term, the HIE Initiative also anticipates incorporating a consumer-based technology, such as a PHR or a patient portal.

In the future, HEALTH, in partnership with Brown University, plans to conduct a well-defined and rigorous evaluation of the HIE Initiative to understand its impact on health care delivery and health outcomes.

It is important to note that progress to date has resulted from stakeholder involvement, a collaborative spirit, and a well-defined source of funding. A broad array of stakeholders, including the workgroups and the State, have offered their time and skills in support of the HIE Initiative. One of the HIE Initiative's most influential stakeholders has been Lifespan – Rhode Island's largest Integrated Delivery Network (IDN). Lifespan is also a major funder of RIQI and maintains close ties with the Initiative, co-chairing its Steering Committee and chairing the technical workgroup. Given Lifespan's size, RIQI, the State, and Lifespan are cognizant of the sensitivities regarding the presence, engagement, and influence of such a large stakeholder. Together, they are working to strike a balance in terms of Lifespan's role and leadership in the HIE Initiative in order to ensure that all HIE stakeholders feel equally represented and are comfortable with Lifespan's role.

The HIE Initiative is also reaching out to physicians directly through Rhode Island's QIO. HEALTH is contracting directly with the QIO, who is responsible for attaining physician input into the project. Specifically, the QIO established an advisory panel comprised of a cross-section of practicing physicians in Rhode Island, including those affiliated with private practices, community health centers, and hospitals. The advisory panel provides input on a variety of issues facing RIQI's HIE steering committee, including program design, training, outreach, and education to physicians.

Finally, the HIE Initiative recently began consumer focused activities. RIQI currently has a community organizer and a consumer representative on the

Board of Directors and is launching a consumer advisory committee to encourage consumer participation in the design and development of the HIE Initiative, and to educate patients about the benefits of data exchange and HIT efforts across the State. However, RIQI, HEALTH, and the other HIE subcontractors (the QIO and a public relations firm),

have struggled with what “type of consumer” to include on the RIQI Consumer Advisory Committee – an average individual, a consumer advocate, or a consumer organization. Additionally, HEALTH has contracted with the public relations firm to conduct focus groups and consumer outreach to determine how best to target, inform, and engage consumers.

Financing and Sustainability

The HIE Initiative’s five-year, \$5 million AHRQ State and Regional HIT contract is fundamental to the program’s existence and development. The AHRQ contract is the primary source of funding for the HIE Initiative which absent the contract, would likely not have been possible. The contract will initially be used to support the development of the technology infrastructure, outreach activities, governance, oversight, Statewide coordination, and long-term evaluation. Most recently, the HIE Initiative also received a \$96,000 contract from the Robert Wood Johnson Foundation to support HEALTH in developing community standards for data exchange, and to enable HEALTH to migrate its data to a selected data standard to be part of the HIE.

RIQI expects all stakeholders to benefit from the HIE Initiative. However, to date, RIQI and the HIE Initiative have not yet identified a model that will support long-term fiscal sustainability of the HIE

“We pulled key stakeholders together and everyone had a different view on what they were trying to sustain.”

Initiative. The interviewees acknowledged that a sustainable HIE model needs to include all “people who are paying the bills” and should derive the amount organizations would be expected to pay from the benefit they would receive. Currently, RIQI is looking at different models and talking with a variety of other HIT initiatives to better understand what exists and how it is working. Acknowledging that sustainability is a challenging issue and more work needs to be done, RIQI is establishing a sustainability committee, chaired by the Rhode Island Health Insurance Commissioner, that will identify and develop an effective approach to meet the needs of the varied stakeholder groups.

Challenges and Lessons Learned

Despite support from an array of stakeholders including the State and RIQI, the HIE Initiative has encountered a number of challenges along the path toward implementation. One of the greatest challenges it has managed thus far is RIQI’s role and integration with the State. HEALTH is a State agency that is trying to develop and implement a project which is community-based, requires significant stakeholder input, and ultimately will be operated by the community—outside of State government. The interviewees acknowledged that some people are having difficulty understanding that the State, in collaboration with RIQI, is building the HIE to be owned and operated within the community. The HIE Initiative has also experienced delays because of the need to adhere to regulations surrounding State purchasing and procurement.

These processes are often lengthy and less efficient than private sector transactions.

Additionally, the HIE Initiative must balance the concerns of its diverse stakeholder group with those of the State and is working to build an infrastructure that will support all stakeholders. However, this often means starting implementation with the groups that are willing, able, and ready to embrace the technology. These same groups are often the ones most technologically advanced. Therefore these groups may not raise the same questions as stakeholders less familiar with HIE or less capable of embracing the specific technologies.

Finally, the HIE Initiative faces a logistical challenge of coordinating the legal, technical, political, and

management components that accompany the data exchange. The interviewees acknowledged the tremendous amount of interplay that exists across the issues and the constant efforts to balance perspectives and synchronize the timing of the various components to ensure that the project is carried out as smoothly as possible.

The State, in particular, has helped to lead the way—providing project management and oversight, and serving as a facilitator to help the HIE Initiative define and articulate the role for community partners. Additionally, the State is a data sharing partner, contributing data from HEALTH and Medicaid.

Medicaid officials are also part of the Initiative's leadership team and the Medicaid Director will be chairing a RIQI Committee focused on making administrative health data available to providers from one single location which could also serve as a portal to clinical information.

Though the mix of diverse stakeholders poses many challenges to the HIE Initiative, its strong support signifies that much of the State is vested in the success of the program. The interviewees noted that this broad-based support has helped the HIE Initiative obtain the necessary support, attention, and funding to promote HIE in Rhode Island.

Spotlight on State HIE Activity: Rhode Island

- *The SureScripts Electronic Prescribing System* is a collaborative effort between independent and chain pharmacies to promote Statewide electronic connectivity between physicians and pharmacies nationwide. Rhode Island served as the national beta test site for this SureScripts system.
- *EHR RI* is a for-profit, implementation and support organization comprised of physician leaders representing 50% of Rhode Island physicians. This organization is working with a

single vendor to implement and maintain an EHR system for interested Rhode Island physicians.

- *Governor's Healthcare Agenda*—the Governor recently unveiled a five-point health care agenda which included a major focus on HIT. A State HIT issues team has been created and is working in collaboration with RIQI to achieve “Anywhere, Anytime Healthcare” throughout the State by 2010.

Statewide Convener

RIQI serves as a coordinating body for Statewide HIT activities and encourages collaboration between projects to fuel broader HIE adoption. This role is clearly stated in RIQI's mission “...the Quality Institute will promote coordination and collaborative relationships, increase value to purchasers and improve the overall quality and safety of health care in Rhode Island.”

In its role as a convener, RIQI will work to build sustainable Statewide HIE and interoperability and

ensure adoption of EHRs as a foundation for improved quality care. Over time, RIQI will look for opportunities to ensure that the variety of HIT activities in the State are in some way collaborating to promote HIE or HIT adoption. With a broad base of stakeholders and State government involvement, RIQI intends to ultimately leverage its influence to effectively facilitate and convene HIT activities in and across the State of Rhode Island.



MidSouth eHealth Alliance: The Memphis Initiative

Dates of Note	<ul style="list-style-type: none"> 2004: MidSouth eHealth Alliance established 2004: Memphis Initiative launched
Overall Program Objective	<ul style="list-style-type: none"> Establish Statewide data exchange across Tennessee with an initial focus on select hospital emergency departments.
Engaged Stakeholders	<ul style="list-style-type: none"> State Government including Medicaid Regional Medical Center Academic Medical Center Hospitals Consumer-Business Coalition
Target Population	<ul style="list-style-type: none"> One million Tennessee residents in three counties and 100,000 people in adjacent States
Technology/Infrastructure	<ul style="list-style-type: none"> CDR Regional MPI Initial project – real-time data across hospital EDs
Funding	<ul style="list-style-type: none"> Federal—\$5 million over five years State Appropriations—\$8.7 million Vanderbilt University—\$750,000 (in-kind)
Timing	<ul style="list-style-type: none"> Pilot program testing data exchange to begin first quarter 2006
Unique Program and State Features	<ul style="list-style-type: none"> Major involvement of a leading academic medical informatics group Established technology infrastructure Heavily driven by State Medicaid program AHRQ State-Regional Demonstration Grant recipient

Overview

The MidSouth eHealth Alliance, an HIE project in Memphis, Tennessee, is striving to establish a model for Statewide data exchange in Tennessee beginning with data exchange across Memphis-area hospitals. In 2004, Tennessee's Governor Bredesen, founder of HealthAmerica Corporation,¹⁵ launched the Volunteer eHealth Initiative as a direct response to the State's health care situation—which included a failing regional medical center; Statewide challenges to providing safe, appropriate cost-effective care in Tennessee, especially for Medicaid beneficiaries; and most notably, the Bureau of TennCare's fiscal crisis. Tennessee stands alone when compared to the problems in many

other State Medicaid programs. The interviewee noted, that even in a State with no income tax, TennCare covers close to 500,000 individuals who would be uninsurable in other States. Recognizing that information exchange and an HIT infrastructure could be instrumental in addressing these challenges, Governor Bredesen issued an executive order to create the Volunteer eHealth Initiative, which became the MidSouth eHealth Alliance. The State of Tennessee is also supporting several other HIT projects across the State.

Governor Bredesen and the Commissioner of Finance and Administration, Dave Goetz, were particularly engaged in the early planning phases of the MidSouth eHealth Alliance and have continued to provide their leadership and support as it moves toward implementation. Plans are currently under

¹⁵ HealthAmerica Corp. is a publicly traded, Nashville-based health care management company that eventually grew to more than 6,000 employees.

way to incorporate the MidSouth eHealth Alliance as a 501(c)(3) and to change the incorporated initiative's title to The Memphis Regional Health Information Organization. The new RHIO will be

governed by major stakeholders and members of the community and will set policy and provide governance for HIT activities across the State.

Planning and Implementation

Planning The five goals of the MidSouth eHealth Alliance, as charged by the Governor, are to:

1. Increase access to necessary clinical information to improve care;
2. Understand the organizational, financial, legal, and technical barriers impeding the development of regional health information infrastructures;
3. Study the costs and benefits of these initiatives;
4. Implement and evaluate interoperability standards required for a national health information infrastructure; and
5. Develop a public-private market for interoperable HIT.

To accomplish these goals, the MidSouth eHealth Alliance established a data exchange project that it refers to as the Memphis Initiative (the Initiative). Data exchange and the supporting CDR will ultimately be accessible at a number of major hospitals, including Vanderbilt University; the Regional Medical Center at Memphis - the State's largest public hospital; and more than a dozen ambulatory facilities.

Through a core set of workgroups with major stakeholder representation, the Initiative identified four implementation issues critical to its success, including: technical design; privacy and security; organizational structure; and implementation. The Initiative also relied heavily on The Markle Foundation's¹⁶ community data exchange resources including models of inter-institutional data sharing and end-user agreements. After testing real-time data flow and addressing security, auditing and authentication issues across the hospitals, the pilot program plans to "go-live" in the first quarter of 2006 and will exchange real-time data across EDs in nine of the 12 participating hospitals.

Hospitals, along with Tennessee State and county government, have been major drivers of the

Timeline

July 2004

Governor Bredesen issues an executive order to create the Volunteer eHealth Initiative

September 2005

Workgroups established for governance, technical design, privacy, and security

April - May 2006

ED pilot begins

December 2006

Anecdotal evidence available on the impact of HIE on Medicaid patients

December 2008

Full exchange of core elements among participating entities

Memphis Initiative and have helped to engage physicians, labs, and other members of the provider community. The Initiative has also involved a key set of clinicians from the stakeholder institutions as part of its planning committee to provide input and identify initial target areas and priorities for the Initiative. However, they have been wary of heavily engaging physicians in the program's early stages—a key distinction relative to other States' approach.

The Initiative is an infrastructure effort that will help to stimulate the EHR environment, reduce costs for physicians' EHR use more broadly, lower barriers to entry, and increase the value, but they do not see the Initiative "rolling out" into physician offices in the near term. The interviewee also acknowledged that participating hospitals are working to strike a delicate balance with physicians. They want to maintain a solid relationship with their physicians but do not want to unrealistically elevate physician expectations amid an atmosphere crowded with reimbursement cuts and office practice technology efforts. Much development in

¹⁶ http://www.connectingforhealth.org/resources/cfh_topic_list.pdf

information security, confidentiality, and interchange standards must be completed before any potential can be realized. The Initiative does not want to engage physicians broadly until the true potential of the Initiative is understood and early pilots are operational.

In determining its priorities, the Memphis Initiative identified hospitals as part of its core membership and recognized EDs as the most appropriate starting place, given the potential return on investment (ROI) to hospitals and payers from reduced duplicative services, and inappropriate or uncompensated care. Initiative leaders felt confident that if more information were available at the point of care hospitals could minimize inappropriate and costly care.

The interviewee acknowledged the value and importance of including other stakeholders groups not currently participating in The Memphis Initiative,

Implementation During its existence, the Memphis Initiative has moved from an intense planning phase to a testing phase, and will soon move into implementation by piloting real-time data exchange across a set of hospital EDs.

Currently, the Initiative is targeting one million citizens of three counties in Tennessee, but it recognizes the potential to eventually focus on more narrow populations to manage care for conditions such as sickle cell anemia, Group B strep, and other chronic diseases. The ED pilot is expected to broadly support the provision of appropriate and cost-effective care, and is laying the foundation for widespread data sharing across the State.

The supporting technology and data infrastructure in the Memphis Initiative was created by, is housed at, and has been used by Vanderbilt University for the past 13 years. The technology, which is described as a regional MPI, allows hospitals to “publish” their data in their own format into an isolated “data vault” under their own control. Then, through the use of business logic and other authentication measures; the technology makes it available for providers to view at the point of care.

Although physically housed in a single secure facility, the architecture is more “decentralized” than “centralized” in terms of its design. The system

such as consumers, mental health providers, ancillary providers, and long-term care populations. However, he also indicated that in many cases, it is simply too early to engage these groups. He stressed the need to overcome a number of issues, prior to engagement, including confidentiality, security, and demonstrated value for these stakeholders.

The interviewee also emphasized the value and importance of the Initiative’s Business-Consumer Coalition which was the catalyst for a failed Community Health Information Network (CHIN) effort a decade earlier and remains active in the Leap Frog Group efforts. The Business-Consumer Coalition is involved in the HIE Initiative, but not at the governance level. The interviewee believes that ultimately this group will be able to leverage its power as a payer in promoting plan and provider participation.

“To be successful, you must consider the broader population in establishing an HIE initiative—it cannot be created solely to support the Medicaid program, as many non-Medicaid populations across the State will access the same services and sites of care.”

allows the physician to look up a patient by name and then integrates data for that patient across the potential sites of care by pulling from a CDR. The information is captured and sent electronically between hospitals and encompasses a variety of data including hospital reports; medication data; pulse oximeter readings; discharge summaries; and claims data. With the broader adoption and use of standards, the infrastructure will support the bi-directional exchange of data between hospitals and ultimately will be integrated into a wide range of CDR and ambulatory care practice systems. Other ongoing implementation efforts include the development of an algorithm for a RLS and assessment of the technology design and the hardware specifications.

Designed by Vanderbilt University, the Memphis Initiative does not explicitly intend to keep the technology proprietary or internally managed over the long term. The interviewee indicated that a

primary goal of the AHRQ contract is to advance the development of open, standards-based systems. While the Memphis Initiative does not currently maintain any relationships with vendors, the technology is designed to be “100% open,” and ultimately will be replaced by a commercial technology. It is interesting to speculate though, that if Vanderbilt did not provide the infrastructure, it is likely that at least one major vendors would step forward and provide technology for parts of this market. The interviewee noted that at this early juncture, any vendor efforts to dominate the market might cause a greater degree of resistance from

“Memphis’ job is not to necessarily solve all the eRx and HIT issues in the State but to take the best minds to help analyze and determine exactly what the issues are and how to address them.”

other vendors and could potentially halt data exchange efforts. The Initiative’s proponents believe balanced and open competition is best achieved after the true benefits and costs of the technologies are understood.

Despite some interest at the community level, the Memphis Initiative intends to prohibit in the near term certain usages of the data such as global querying. The interviewee indicated that the architecture is not designed for such queries and will only be adapted through highly secure means to support such access if public health or other needs require it. Community members were concerned that data might be used for report cards, evaluating provider performance, pay-for-performance activities, or other evaluative activities. Although there is potential value in the ability to globally query data, the Initiative felt the concerns surrounding this functionality could erode trust in the project and challenge any efforts to build a coalition.

Financing and Sustainability

The Memphis Initiative received initial funding from the State and Federal governments for the planning and implementation phases. Governor Bredesen appropriated \$1.2 million for the initial planning phase and an additional \$7.5 million for implementation of the Initiative. The Memphis Initiative also received a \$5 million, five-year grant from AHRQ as part of its State and Regional HIT granting program to support development of State health information networks. Additionally, the Memphis Initiative received extensive in-kind donations totaling more than \$750,000 from Vanderbilt University in the forms of technology, staff, space, and supplies.

The Initiative does not currently have an ongoing revenue source or a sustainable business model. The interviewee suggested that there is no

comprehensive sustainable financial model that would not be fundamentally threatening to some participants. Nonetheless, he expects the Mid-South eHealth Alliance, once established as a RHIO, to provide some guidance and support in this area. He also and expects the project to evolve in many ways including, considering pay-for-performance, pay-for-use, or quality programs that will likely influence a more sustainable financing model in the future. Additionally, the interviewee stressed that it will be important for the Initiative to demonstrate cost savings to Medicaid and other delivery systems that comprise a great percentage of health care expenditures before defining the financial model.

Challenges and Lessons Learned

The Initiative has not achieved its success without pushing through a cadre of barriers including legal, financial, and technical barriers; lack of community acceptance and trust; and challenges around data ownership. Initially, the Initiative managed these challenges through strong leadership from the State including the drive of the TennCare program

and through the use of a “neutral” operational technology, but is now managing these challenges through strong local governance. The interviewee emphasized that it is unwise to address financial constraints, especially those within Medicaid, solely with a comprehensive HIT solution such as a regional data exchange, because the technology

requires an upfront investment that may be difficult for these struggling programs to afford. He indicated that partial solutions, through better claims adjudication and eRx systems, may confer almost as much short-term benefit. However, he stressed that HIT can be very useful in addressing other difficulties within the programs, such as quality of care or information flow. HIT can be implemented for those reasons and may simultaneously increase efficiency and decrease the costs of care.

The Initiative credits other aspects of its success to a number of issues including its existing infrastructure and broad stakeholder priorities and goals. The interviewee acknowledged the significant benefit of using an existing system (Vanderbilt) and the progress this system afforded the project. Few projects are able to take advantage of such an infrastructure and therefore expectations on the time and resources required to support even the most basic level of data exchange must be adjusted. He

also indicated that the Initiative's focus on quality—competing with other networks and projects on quality and outcomes, rather than over market presence should not be overlooked. This has allowed all parties to work toward a common goal of quality improvement, and this collaborative competition has encouraged, rather than hampered, attainment of these goals.

The interviewee stressed that Memphis' real achievements are promoting many competing entities to work together, persuading competitors not to compete over data, encouraging competition over value and quality, and encouraging competitors to work together to have better information to care for their patients. It is clear that striving toward common goals with State support and a unified voice has been particularly beneficial for the Memphis Initiative and will likely spur adoption elsewhere in the State.

Spotlight on State HIE Activity: Tennessee

- *CareSpark* is developing collaborative processes to improve the health care in the community and to explore ways to share health information securely, efficiently, and cost-effectively. CareSpark was awarded an ONC contract to develop an architecture and prototype network for secure information exchange.
- *Shared Health*, a for-profit subsidiary of Blue Cross Blue Shield of TN, established a partnership with Cerner to provide desktop systems to physicians to provide TennCare claims histories and eRx software.
- *TLC* of Memphis is a Medicaid managed care plan that is examining how to prevent ED visits by addressing continuity of care issues common after discharge from acute care facilities.
- *University of Tennessee Telehealth Network* provides medical services and medical education in the mid-Appalachia region. This program provides specialty services, chronic disease management, family services, and medical education remotely through video conferencing and patient monitoring technologies.
- *The East Tennessee Health Information Network*, (a collaboration of Knoxville's four major hospital operators - Baptist Health System, Covenant Health, St. Mary's Health System and University Health System), has received some funding from the Patient Safety Institute to investigate regional exchange initiatives.
- *The University of Tennessee, Knoxville* has a Statewide genetics coordination project that works closely with the Memphis initiative and is in turn funded by an AHRQ HIT implementation grant.

Statewide Convener

The Memphis Initiative, the Governor, and State leadership acknowledge the importance of and need for a single entity to support collaboration and coordination across the broad array of Statewide HIT projects. A formal body, the Memphis RHIO, is being created in January of 2006. The Memphis Initiative currently works to identify opportunities for collaboration between its activities and many of the programs described above. It continues to support activities such as Statewide meetings to

facilitate this dialogue although there is some degree of competition across the projects. In addition, clear differences around priorities, business approaches, and objectives also exist.

Moving forward, the Memphis Initiative and the State expect the Memphis RHIO to serve as the Statewide convener to ensure broader coordination of the activities, foster collaboration, serve as a broad State resource, and help to guide data exchange activities throughout the State.



Utah Health Information Network (UHIN)

Dates of Note	<ul style="list-style-type: none"> ■ 1993: UHIN established ■ 1999: UHIN Board decision to expand the Statewide network (UHIN gateway) to support the exchange of other health care transactions (e.g., clinical information) ■ 2004: AHRQ State and Regional Demonstration contract awarded ■ 2004: Utah Department of Health LHII¹⁷ contract award
Overall Program Objective	<ul style="list-style-type: none"> ■ Expand and enhance the current Statewide network (UHIN gateway) for the secure electronic exchange of health care data using standardized transactions through a single portal
Engaged Stakeholders	<ul style="list-style-type: none"> ■ State Government ■ Payers (includes Medicaid and Medicare) ■ Physicians ■ Hospitals ■ Laboratories ■ Pharmacies ■ Consumer Groups
Target Population	<ul style="list-style-type: none"> ■ Utah and bordering States
Technology/Infrastructure	<ul style="list-style-type: none"> ■ Central hub (UHIN gateway) using secure web services infrastructure ■ Considering use of a MPI
Funding	<ul style="list-style-type: none"> ■ UHIN ■ Federal—\$5 million over 5 years ■ State—\$660,000 over 2 years
Timing	<ul style="list-style-type: none"> ■ Web service infrastructure in production 2006 ■ Several pilots which exchange additional health care transactions, including “direct messages” (e.g., laboratory results, medication history, eRx) in 2006
Unique Program and State Features	<ul style="list-style-type: none"> ■ Longstanding HIE ■ Successful history in exchanging claims-based health care data ■ Recognized as a trusted, neutral third party; established stakeholder buy-in and value proposition; existing governance infrastructure ■ Recognized SDO¹⁸ ■ AHRQ State and Regional Demonstration Grant recipient

¹⁷ Local Health Information Infrastructure

¹⁸ <http://a257.g.akamaitech.net/7/257/2422/01jan20051800/edocket.access.gpo.gov/2005/pdf/05-12049.pdf>

Overview

Timeline

November 1993

Utah health care payers, providers, and members of the government form a coalition to reduce administrative health care costs in the State, resulting in the incorporation of UHIN

1993

UHIN employs a dial-up system to exchange claims and remittances

1990's

UHIN members exchange HIPAA related claims and claims-related transactions

1999

UHIN Board decides to expand and enhance its Statewide network to support the electronic exchange of clinical information

2000

UHIN gateway moves to a secure Internet gateway

September 2004

UHIN receives five-year, \$5 million AHRQ grant to expand the current Statewide network for the secure electronic exchange of health care data using standardized transactions through a single portal

September 2004

UHIN receives a 2-year, \$660,000 Utah Department of Health contract for the development LHII

2006

The UHIN gateway moves to a web services infrastructure

The Utah Health Information Network (UHIN) is a not-for-profit organization, owned by its members.^{19,20} UHIN, founded in 1993 by members of the health care community, includes a broad-based coalition of community stakeholders consisting of

¹⁹ <http://www.uhin.com/about/members.htm>

²⁰ Careful readers will note that the presentation on Utah differs slightly from the other State case studies, reflecting UHIN's preferred format for the discussion of their unique and important program.

physicians, provider institutions, payers, employers, and State government.

Recognizing the efficiencies and cost savings that information exchange and electronic commerce transaction processing brought to bear for the business, banking, and transportation fields several decades earlier, UHIN members wanted to bring these same benefits to Utah's health care industry.

UHIN's Stated mission is to reduce health care costs, improve quality and access, and facilitate research by:

- Using standardized transactions, which are developed by the community, in exchanging electronic health care information;
- Allowing members to use a single secure portal to electronically exchange health care information in the community; and
- Educating UHIN members, at no charge, about health care transactions, security, privacy, etc.

UHIN's founding members saw an immediate and long-term business case in standardizing claims and claims-related (e.g., eligibility, remittance advice, reports) health care information to be exchanged through a single portal (UHIN gateway).

Although UHIN is a not-for-profit organization, it only provides services which have business value for its members and for which members will pay. UHIN has a self-supporting business model,²¹ which includes:

- Membership fees for providers; and
- Per-claim transaction fees for payers. Claims-related transactions are included in the claim transaction fee.

The UHIN board always had the vision of exchanging all types of health care information (e.g. claims and clinical data) but claims and claims-related transactions have been the primary focus of implementation. In 1999, however, the UHIN Board made a decision to expand and enhance its Statewide network to support the electronic exchange of additional health care information (e.g. clinical information).

²¹ <http://www.uhin.com/start/UHINet%20Attachment%20A.pdf>

“UHIN is becoming a complete HIE, not just a claims and claims-related exchange or just a clinical information exchange.”

In 2004, UHIN became an AHRQ State and Regional Demonstration grant recipient. The purpose of the grant was to expand and enhance the current Statewide UHIN gateway for the secure

electronic exchange of health care data using standardized transactions through a single portal. The interviewee emphasized that the AHRQ grant has been a catalyst that enabled the development of additional health care information exchange in Utah.

Accordingly, UHIN will utilize its existing organizational processes among community stakeholders to develop new health care transaction standards, many of which are clinically focused.

Planning and Implementation

UHIN provided the following outline for its planning and implementation activities:

“Protected health information is protected health information.” UHIN does not make a distinction between claims and clinical exchanges.

- Phase One
 - » Enhance the existing UHIN gateway using a standardized web services architecture.
- Phase Two
 - » Exchange of standardized direct messages. Direct messages are where the submitter knows who the receiver is (e.g., laboratory results from a hospital to a specific provider).

UHIN members have identified several different direct messages, which will support the second phase of the project:

- » National Council for Prescription Drug Programs, Inc. (NCPDP)²² transactions
 - Medication history
 - Formulary and benefit insurance information
 - eRx

²² www.ncdp.org

- » Health Level 7 (HL7)²³ transactions
 - Attachments
 - Laboratory orders and results
 - Public health reporting
 - Chart notes
 - Clinical reports, etc.

The initiatives for direct messages are at various stages of implementation. Most are developing data standards, while others are still in the planning and prioritization phases. There is also a current pilot project under way which includes the exchange of de-identified chief complaint data. In this pilot, chief complaint information is collected when a patient is admitted to the emergency department. The chief complaint information is exchanged under the State’s biosurveillance and public health efforts to track outbreaks and monitor disease in the community.

- Phase Three
 - » Implementation of a MPI. While the UHIN gateway is the platform that provides the means by which users connect and exchange messages, a MPI has the potential to provide new services to UHIN members.

²³ www.hl7.org

Financing and Sustainability

UHIN has been self-sustaining since its inception, and it is UHIN’s intention that all clinical transactions will also be self-sustaining. UHIN is supporting this project by sharing infrastructure, governance, and expertise.

UHIN has received a \$5 million, five-year contract from AHRQ as part of the State and Regional Demonstration project and a \$660,000, two-year contract from the Utah Department of Health. Both awards will facilitate the exchange of multiple types

of health care transactions using UHIN's web services infrastructure.

UHIN is currently working with other AHRQ contract sites, including Indiana, Tennessee, Rhode

Island, Delaware, and Colorado, and the local health care community to identify strong business value for HIE and models for self-sustainability.

Challenges and Lessons Learned

UHIN has experienced some of the common challenges faced by HIE projects including security, privacy, uniquely identifying patients, authentication of users, routing messages, and the lack of consistent data and message standards. UHIN convenes the community to address these challenges and to address specific UHIN member concerns.

UHIN believes that responding to and managing these challenges is critical for long-term success, and that demonstrating value to one's members will be critical for the success of any HIE project. Strong leadership and community buy-in are also essential qualities for success. HIE projects must develop a community vision and a strong business value to secure vested community interest, and

develop trust among the many stakeholder entities; all of which require planning, organizing, and collaborating with the community.

To help HIE projects sustain themselves financially and achieve a positive ROI for their members, UHIN also believes HIE projects should require high-volume transactions. An example of this for UHIN has been the claim transaction. In a not-for-profit model, high-volume transactions benefit the stakeholders because they allow for lower costs per message transaction. However, the interviewee noted that clinical exchanges are more challenging because their value is diffused among many members.

Spotlight on State HIE Activity: Utah

- *University of Utah* is assessing the value of a computerized clinic order entry tool in rural primary care practices.
- *International Severity Information Systems, Inc.* is using HIT to implement a best practice decision support module in nursing homes and is evaluating clinical, efficiency, and satisfaction outcomes.
- *Doctor's Office Quality-IT*, a partnership between CMS and State QIO's, is working to promote HIT adoption in physicians offices.

Statewide Convener

By virtue of its mission to bring together multiple stakeholders for the purpose of facilitating HIE, UHIN is able to serve as a central convener in the State of Utah. In the more than ten years since its

formation, UHIN has established itself in the health care community and is perceived as a trusted, neutral third party entity that offers a valuable service and infrastructure for HIE.

Success and Sustainability

As the case studies demonstrate, many HIE projects share common goals and overarching objectives, yet vary on their strategy and implementation plans. Despite these differences, interviewees seemed to agree on a set of criteria for success (for both planning and implementation) and what will likely be necessary for long-term sustainability—a position that most of these projects are still pursuing.

Success: Planning and Implementation

All eight State projects identified the following factors as critical to initial planning and early implementation stages:

- State’s role as a catalyst (including leadership support)
- Broad stakeholder inclusion (including early engagement of physicians and physician champions)
- Clear value proposition with early “wins”
- Technological Interoperability

State’s Role as a Catalyst

In each project, the driving stakeholders varied considerably (e.g., State government, community hospitals, and local employers). This variation speaks to the uniqueness of each individual community, its priorities, and the engaged stakeholders. In most projects, support and engagement by multiple agencies within State government was viewed as a major catalyst and an essential component to generating momentum, credibility, and stakeholder buy-in in the HIE projects.

Broad Stakeholder Inclusion

It is clear that each community initiative must determine stakeholders central to its mission and relative to its own priorities and objectives. However, the project interviewees repeatedly

“Inclusiveness should be the ultimate goal, even if it is at the expense of moving quickly.”

stated that within that framework, they sought involvement and collaboration from a cross-section of health care stakeholders, often stressing that early physician involvement and the presence of physician champions were imperative to promote credibility and to facilitate engagement of other physicians. Many projects also recognized the need for financial incentives to promote physician HIT adoption and have included this in their implementation plan.

Clear Value Proposition with Early “Wins”

Many project leaders indicated their commitment to identifying the “value proposition” for all involved stakeholders and saw this as essential to enabling successful implementation. Some projects such as Hawaii and North Carolina are still striving to identify the value proposition for their multiple stakeholders. As the projects work diligently to identify and articulate their broad plans and develop strategies for implementing HIT and promoting its use, many interviewees stressed that the importance of finding opportunities for quick successes and that demonstrating short-term wins cannot be overstated.

Technological Interoperability

An interoperable infrastructure – a shared goal of these State projects – is also critical for success. Avalere’s research showed that every project is working toward this in some way, whether through a MPI, a RLS, or a distributed or centralized data repository. A shared mechanism by which any community supports communication across varied technologies is necessary for success. It is no surprise, given the complexity of interoperability, that each State project is still navigating this in some way. It is

“Try to find an easy first (project) that showcases the ROI or real benefit, easily and quickly.”

worth noting that some of the challenges of identifying and implementing the right infrastructure and design are linked to privacy and security issues (e.g., whether or not to involve consumers and; whether to use a centralized or decentralized architecture).

It appears that smaller communities can look to leverage a single vendor more easily than large States; however, only with interoperable infrastructures across these HIE project will long-term sustainability be achieved.

Evolving State Role

As previously discussed, there are a number of roles for States to play in the context of HIE, including serving as a convener, facilitator, funder, data source, and project partner. To support efficient implementation of HIE, interviewees indicated that a State vision and strong leadership will be essential for long-term success. It may also be true that eventually, the State may need to step back from a primary leadership role to one of shared leadership to allow a representative third party to emerge. This is the case in Tennessee in the context of establishing a sustainable interoperable infrastructure.

Given the local nature of RHIOs, and the potential for competition, the responsibility of promoting and ensuring coordination across RHIOs is likely to fall to the States. As the number of RHIOs continues to rise, and the degree of information exchanged increases, some level of collaboration and communication across these various entities will be critical to promoting more efficient, cost-effective, and better quality of care.

Long-term Sustainability and Financing

While many of the interviewees discussed their project's progress and success within the planning stages or in moving from planning to implementation, the majority of interviewees could not articulate their project's long-term sustainability or tested revenue models. The exceptions were UHIN and NCHICA which were able to discuss their value proposition and sustainable organizational models for their previous activities to date. UHIN's financing model for administrative transactions may be the closest to the sustainable framework States are seeking.

Without a doubt, long-term sustainability and financing appear to be the most challenging and, in most cases, unknown aspects of these initiatives. Some initiatives are discussing a variety of alternatives; many are looking to other programs for models and insights, while for some, financing and sustainability remains a notable obstacle. For established HIE initiatives considering specific strategies, the most common strategy appears to be a data fee model where subscribers pay a fee to access the data and participate in the HIE. This fee is proportionate to the benefit subscribers will receive from the project. For example, employers and payers frequently reap a greater benefit than providers, and therefore would pay a higher fee. The fees, how they are calculated and collected, and when they begin, vary across projects but in all cases are not yet in effect. In some instances, fees are expected to be collected beginning later in 2006. Questions about how much, if any, consumers will pay for access to EHRs or PHRs also loom as untested territory.

Many of the initiatives do not have fee structures or revenue models in place, yet the interviewees stressed that once they understand how HIE will benefit the varied stakeholders and individual organizations they will be able to better understand how fiscal responsibility can be equitably shared. Ultimately, HIE projects need to demonstrate that HIE will improve care for patients, make the processes easier, more efficient, and more effective

“There is great competition for healthcare funding. Given that 100% of health dollars are consumed somewhere, it is unreasonable to think that those who get the dollars will easily give them up if they are not somehow part of a ‘sustained’ initiative, even if such a relationship is less than optimally efficient to the community.”

for stakeholders, particularly physicians. Today, it appears that all projects are seeking additional support in navigating these project complexities and long-term sustainability.

Industry Considerations

Many interviewees indicated a desire to have all interested stakeholders involved, particularly those that will roll up their sleeves and tackle the hard to solve problems. There are wide array of opportunities for interested stakeholders to help formulate, develop, and actively participate in the growing set of HIE activities to promote Statewide, and eventually nationwide, HIE. Given the array of projects, stakeholders should step back to assess what aspect of real-time HIE will be of greatest value and get engaged in the initiatives that are of greatest interest and value to their organizations and to them as individuals.

Another industry consideration is that there is no single definition for a RHIO, nor is there a single entity that accurately and completely characterizes a RHIO or its activities. The authors would assert that RHIO is the latest term for a multi-stakeholder entity that is focused on supporting and achieving HIE. Some industry sectors are advocating for a standard definition of these entities. However, based on in-depth discussions with various HIE projects that have RHIOs or that are “RHIO-like,” the authors believe it is premature to establish a standard definition or set of roles and responsibilities for these community-based organizations. Given the varied nature of communities and their projects, it is questionable if defining a RHIO will be a helpful endeavor.

Unique Roles for the States

Based on discussions with representatives from the selected projects, it is clear that the State can provide a range of significant support to HIE projects. The State’s role could not easily be performed by another stakeholder and in some instances, only a State could provide certain support. The following are some of the unique roles that States can play:

- In Medicaid and public health agencies, States maintain unique population-based data necessary for HIE projects, particularly for vulnerable populations.
- State regulation can create barriers to project goals, however this was not evident in the case study findings.
- As noted above, the State is sometimes the sole initial funder and provides some of the initial administrative infrastructure for project pilots.

Federal Activity: Context For State-Based HIE

Historically, the Federal government has interacted with States on HIT in only a few standard ways, including grant programs and program infrastructure, such as MMIS. However, a number of key factors have fostered support of HIE in the health care industry, at local community levels, and throughout Congress including:

- The creation of the Office of the National Coordinator (ONC) for Health Information Technology in 2004;
- AHRQ’s HIT grant program and Resource Center; and
- The sustained high-level support in 2005 from the Bush Administration and the Department of Health and Human Services (HHS) on the need for HIT and a national interoperable infrastructure to support HIE.

The Federal government has made it a top priority to have national EHRs in ten years and is promoting HIE across Federal agencies.

While this report is focused on the growth of State-based HIE activities, it is important to acknowledge that this volume of activity is occurring during a period of increasing Federal activity. This report captures a “snapshot in time” of national activities supported by the Federal government. This glance at relevant

Federal activities provides the reader a context within which States are developing their specific HIE initiatives.

AHRQ

AHRQ serves a unique role in the Federal government's commitment to facilitate HIE and HIT adoption. AHRQ's mission is to improve the quality, safety, efficiency, and effectiveness of health care for all Americans. The Agency achieves this mission by supporting a broad program of health services research and by working with partners to promote improvements in clinical and health system practices. In addition to various HIE stakeholders, end-users of AHRQ research include, clinicians, health care systems, and leaders at the Federal and State level.

AHRQ's commitment to working with States includes disseminating relevant research findings and providing information and assistance to States to put research on health care quality into practice. With respect to advancing HIE and HIT, AHRQ funds a number of State-based activities to promote research, HIT adoption and information exchange, and to broadly improve patient safety and quality of care.

Through AHRQ's HIT initiatives and grants program, the agency is an integral player in meeting the President's ten-year goal of wide-spread EHR adoption. AHRQ administers more than \$166 million in grants and contracts throughout 41 States to support and stimulate investment in HIT (especially in rural and underserved areas), increase adoption of HIT systems, improve patient safety and quality of care, and conduct research on challenges to adoption and use. AHRQ also strives to identify solutions and best practices for HIT.

The first of three major components of AHRQ's HIT funding is: The Transforming Healthcare Quality Through Information Technology (THQIT) initiative—a set of grants to support planning, implementation, and evaluation of HIT. AHRQ also awarded contracts to six States (Colorado, Delaware, Indiana, Rhode Island, Tennessee, and Utah) to assist in the building of Statewide and regional health information networks. Recipients of these and other AHRQ HIT grants form a “nationwide learning laboratory” for developing and testing new HIT applications.

Secondly, AHRQ has funded a multi-million dollar, multi-year contract to support the AHRQ National Resource Center for Health Information Technology (the National Resource Center) to facilitate the sharing of new knowledge and other findings that have the potential to transform everyday clinical practice. Lessons learned from the many AHRQ grantees are disseminated through the National Resource Center, with the goal of increasing communication and advancing the efforts amongst hundreds of HIT and HIE projects across the country. HIT projects and those funded by other Federal partners also receive support, direct technical assistance, and consulting services from the National Resource Center during all phases of their work to develop and implement HIT systems and infrastructure.

Finally, AHRQ, in support of ONCs efforts has made a significant investment – \$11.5 million in fiscal year 2005 – to assist emerging HIEs with questions about privacy and security issues.

Office of the Secretary, The Community, and ONC

There have been a number of significant HIE activities led by the Secretary of HHS and ONC which focus on fostering interoperability and resolving connectivity issues.

In September 2005, the Secretary formed the American Health Information Community (The Community). The Community is a federally chartered, public-private sector group charged with recommending actions and providing advice to accelerate the widespread adoption of HIT. Commissioners who serve on the Community represent various stakeholder interests in the advancement of HIT.

The Community will make recommendations for priority areas, or “breakthrough” projects, in which HIT can produce a tangible and specific value to the health care system and consumers that can be realized within a two to three year period. The Community will engage external experts for advice and participation on

workgroups to inform its decisions and agenda around the breakthrough projects. With the help of commissioners from other Federal agencies, the Secretary intends for the government to lead by example and to advance the market for HIE.

To further this mission, The Community will work closely with a consortium of four contractors to whom ONC and AHRQ have awarded several infrastructure RFPs focusing on:

- Standards harmonization;
- Certification and compliance; and
- National health information network (NHIN) prototypes.

Combined, these contracts total over \$36 million, and the collaboration between these contractors and The Community—coupled with their work products—are intended to serve as catalysts to achieve the President’s goal of widespread adoption of interoperable EHRs by 2014.

The NHIN contractors²⁴ will each develop a prototype network for secure information sharing among hospitals, laboratories, pharmacies, and physicians in participating markets. These contractors will also collaborate to ensure that information can move seamlessly between each of the newly established networks. This interconnectivity will form a single infrastructure among the consortia for HIE, and lay the groundwork for a national network through which additional States and RHIOs could connect to share health information.

While these contracts will ultimately yield results that have the significant potential to advance HIE for all States throughout the country, other HHS initiatives are designed to garner specific input from many States. AHRQ's privacy and security contract, which is a joint AHRQ/ONC²⁵ project, was awarded to RTI International. It is a single contract having up to 40 subcontracts with designees of State or territorial governments to review enterprise-level business practices related to privacy and security, identify best practices, and develop solutions for challenges to achieving smoother transmission of health care data.

The increased activity in AHRQ and the Office of the Secretary is mirrored by extensive activity across other HHS agencies. The other agency activities that will affect State projects and initiatives are briefly described in the table below with more detail provided in Appendix A. Although the range of Federal activities in many respects reflects the range of State activities, the pace of these activities may need to be balanced with the realities of the community and the State-based HIE projects.

Agency	Activity / Initiative	Description
AHRQ	HIT Grants and Resources	AHRQ funds a number of States to research and increase HIT adoption and to improve patient safety and quality of care. Its National Resource Center facilitates the sharing of new knowledge, findings, and lessons learned from HIE initiatives across the country.
CMS	Administration of the Medicaid Program	Medicaid’s HIT focus has historically been the Medicaid Management Information Systems (MMIS), which supports claims processing and facilitates information retrieval for the State Medicaid programs. The Agency is now working with States to implement MITA, which is intended to foster integrated business and information technology transformation across the Medicaid enterprise in order to improve program administration.
	eRx and EHR Adoption	CMS and the Office of the Inspector General released two proposed rules to help facilitate the adoption of HIT and HIE nationwide through exceptions to the Stark rule and safe harbors under the anti-kickback statute that would permit the donation of items and services related to eRx and EHR technology.

²⁴ These markets include: Kentucky, Tennessee, and Virginia; Indiana, Massachusetts, and California; New York, Research Triangle Park in North Carolina, and Rockingham County, North Carolina; and Santa Cruz, California, Cincinnati, Ohio, and Cleveland, Ohio.

²⁵ The funding and project management rest at AHRQ.

Agency	Activity / Initiative	Description
	eRx Foundation Standards	CMS published the final rule on foundation eRx standards that are mandatory for Part D sponsors. CMS has also funded eRx pilots to test a broader set of eRx standards and evaluate the impact of health care outcomes.
	PHRs	CMS issued an RFI to solicit input on what role the agency should play in the development and use of PHRs.
	Quality Demonstrations	Doctor's Office Quality-Information Technology pilot program is intended to support the adoption and appropriate use of HIT in small- and medium-sized physician offices; and the Medicare Health Care Quality Demonstration Program is intended to develop, test, and disseminate major and multi-faceted improvements to the health care system.
	Medicaid Waivers	Home and Community Based Services waivers afford States the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, oftentimes using HIT.
CDC	Biosurveillance	Public Health Information Network is intended to provide the nation with integrated public health information systems for biosurveillance in order to counter national civilian public health threats.
HRSA	HIT Grants	Telehealth Network Grant Program provides grants to develop telehealth network projects in rural and medically underserved areas.
NLM	HIE Grants	Provides grant support for developing integrated advanced information management systems that facilitate HIE.

Implications

The rapid expansion of Federal, State, regional, and local HIE projects creates new State and Federal implications and opportunities. The findings of this paper point to a future HIE debate centered around issues of leadership, funding, long-term sustainability, the appropriate role of government, and how to best achieve interoperability.

Broadly, stakeholders and decisionmakers will have to address:

- What role should the Federal and State government play in promoting specific HIE projects?
- How should lessons learned and models of success be shared most effectively and efficiently across States?
- How will the various public priorities and needs – Federal, State, and local – be balanced in the context of locally-driven initiatives?
- Are lessons learned at the State level appropriate for shaping Federal developments? How heavily should State experience be weighed in national HIE debate?
- In its role as a convener and catalyst, are there ways government entities at the State and Federal levels can facilitate HIE coordination and interoperability in an equitable manner?

The success of State-based HIE projects is heavily dependent on both adequate and sustainable funding sources, as well as robust mechanisms for stakeholders at all levels to engage constructively with one another. Most State-based projects will continue to look for and rely upon outside funding in the early stages, but it is clear that additional work will be necessary to identify new funding mechanisms to support HIE projects over time. It is also vital that lessons learned on the varying successes of collaboration models be shared quickly to maximize the potential of HIE.

State and Federal decisionmakers will need to continue to consider realistic funding estimates to promote and advance HIE at the community level. The absence of credible and agreed-upon estimates suggests

the need for additional research in this area. In light of the estimated total costs and the varied value propositions of the HIE infrastructure, new funding approaches should be developed and/or identified. It will also be important for State and Federal leaders to examine the relationship of Medicaid's reimbursement structure and other funding opportunities in addressing this question.

Finally, and distinct from direct funding needs and opportunities, State and Federal decisionmakers may wish to consider other means to support and promote HIE adoption, including serving as educators, conveners, and facilitators of Statewide HIE activities to promote cross-fertilization of projects, shared learning, and program successes across States, regions, and communities.

State Opportunities

The long-term goal of most of the profiled case studies is fully interoperable HIE. To achieve that goal, States must remain focused on successfully promoting and facilitating broad stakeholder involvement, promoting coordination and collaboration of HIE activities Statewide, and supporting Statewide HIE in an equitable manner. The latter may be challenging for some States, given the potential sensitivity and level of scrutiny that may be applied to the State, particularly in the context of funding competing projects. States will likely have to balance this sensitivity against the State priorities and plans around HIE broadly. Ultimately, States may shift toward a more shared leadership role to allow a representative third party to emerge.

In particular, States can:

1. Provide leadership, through the Department of Health, the Medicaid agency, the Governor's office, or other State agencies, to help set the HIE agenda and direction for the State. Each case study shows alternative ways States can take a leadership role.
2. Promote broad stakeholder involvement and serve as a neutral third party to facilitate communication, decision making, and shared learning across a wide array of entities, particularly with respect to infrastructure initiatives and addressing policy barriers. This can be achieved by providing initial administrative infrastructure (e.g., meeting space); convening and facilitating stakeholder participation through workgroups and in ongoing dialogue for specific HIE projects.
3. Actively participate in HIE initiatives as a data source (e.g., Medicaid, public health, registry data) and as a data partner (e.g., as large insurer or large employer) by exchanging patient/employee data. Through dialogue with other stakeholders, States can provide input into the direction, priorities, and implementation strategy for HIE projects.
4. Facilitate collaboration and coordination across State HIE projects to promote communication, minimize project silos, and most efficiently leverage State funding. Establish and maintain broad-based support for HIE through support of and participation in multi-stakeholder forums and through the development of a long-term vision.

Federal Opportunities to Support States

It will be important for the Federal government and its State partners to promote and build upon current efforts. In particular, the Federal government can:

1. Help convene stakeholders, including State government and Medicaid leadership, at the national level to understand the benefits and impacts of HIE and promote dialogue within or between States, and identify issues and plan for solutions (e.g., sponsor conferences on a monthly and annual basis, either face-to-face or through web and phone forums).
2. Work with and across States by convening stakeholders to facilitate progress, planning, and a shared vision to help them better articulate their needs and identify how they can achieve their goals—whether working through Federal mechanisms (e.g., AHRQ and ONC contracts, breakthrough workgroups,

- agency grants) or working with local stakeholders (e.g., support forums for collaboration and coordination through online meetings for comparable projects or solutions).
3. Bring varied States and project participants together to share learning and models of success (e.g., conduct in-person workshops to educate participants or address and tackle challenging issues such as identifying effective sustainability models or discussing the pros and cons of specific technology infrastructure).
 4. Facilitate common terminology and characterizations of projects to help comparable initiatives identify one another and share experiences.

Given the pace and breadth of HHS activities, including those under AHRQ and ONC, it will be important for the Federal government to acknowledge the individual needs of communities and States and recognize the realities of what is required to implement an HIE infrastructure and exchange data. Ultimately, The Community’s “breakthrough areas” may serve as a general road map and provide prioritization and guidance on areas of focus for initial HIE success, but the exact impact on the variety of State-based activities remains to be seen. It is clear that there is a relationship between the Federal government and the States and the national priorities and communities’ needs for local flexibility that will need to be balanced moving forward.

AHRQ’s Role

For AHRQ, there are new and important opportunities to consider around coordination and direct HIE project support, including growing the ongoing engagements with States and communities, and facilitating dialogue between the Federal stakeholders and the States and communities.

“The role of Federal government is to transform our thinking to pay a lot more attention to the value of outcomes and to have policies that financially support, convene, and promote cross-fertilization.”

Today, AHRQ is serving as a funding agency and working to further establish itself as an evaluator, educator, and convener of HIE projects. Many interviewees indicated that AHRQ should also work to:

- further describe what is happening across the HIE landscape, research;
- evaluate the level of activity to help articulate what is and is not working and why;
- identify replicable HIE and infrastructure models particularly including sustainable revenue models; and
- bring States and stakeholders together to share this information.

AHRQ supports these types of activities in a number of ways, including through its Resource Center. Many State-based stakeholders view AHRQ’s ability to bring stakeholders together to educate, evaluate, and understand the pros and cons of specific HIE issues (e.g., technical infrastructure, governance structures, funding models), and to share learning as critical to the long-term success of HIE.

Additionally, as the need to balance Federal priorities with local communities’ needs becomes more important, AHRQ is well equipped to help resolve any ensuing tensions by serving as a liaison between Federal leaders and States and communities, thus bringing the “community message” and perspective into the Federal dialog.

Perhaps of greatest interest to and for AHRQ in terms of State challenges may be the need to manage the tension of promoting HIT enhancements while simultaneously pursuing new or additional quality measures and reporting issues many of the State projects indicated they are grappling with today. AHRQ should continue to take a leadership role in helping to articulate the debate and the potential mechanisms for balancing these two goals.

AHRQ has a broad portfolio of quality improvement programs that increasingly touch the States. Helping the States understand the implications of a health industry in which needed information is (or will soon

become) available and how that availability will reshape the definition of improved health care quality and efficiency should be one of AHRQ's long-term goals.

Conclusion

Of the eight States studied for this report, no two State projects were alike in scope or core leadership, even though all States were striving toward comparable health improvement goals. Based on initial information about general State HIE projects and further research on the selected individual projects, it appears that planning and implementation timelines may be overly optimistic, underscoring the need for improved State and community information sharing of HIE project details.

Each project continues to struggle with identifying and achieving a sustainable long-term model for funding and implementation, despite having achieved broad stakeholder buy-in. Funding for HIE will continue to be a challenge, and new public and private funding solutions will need to be identified and evaluated.

Perhaps even more critical than the observations made on progress to date-timing, and funding are the potential disconnects between the Federal priority for expedited HIE adoption and the realities of local implementation. The variance in State approaches and successes points to specific opportunities for the Federal government to support sustained State-based HIE evolution. These include providing enhanced funding, facilitating shared rapid learning, and continually balancing national goals with State and local realities. States are looking to AHRQ as a critical, credible partner for support with shared learning and project evaluation.

It is clear from the breadth of activity, the variability, and the fast-paced push from the Federal government, that opportunities are ripe for stakeholder participation and influence. It is also clear that the entire health care community will need to develop a consistent, common mechanism for capturing, sharing, and understanding this growing market and its impact on care delivery.

Future Research and Analysis

The current level of HIE activity and the degree of questions and issues raised throughout this report suggest the need for specific support on a range of topics. Below is a set of issues the authors recommend for attention from Federal, State, and industry leaders. However, this list is only the beginning and may vary depending on a stakeholder's perspective and priorities.

- Establish and evaluate communication mechanisms for shared learning;
- Support State efforts to balance multiple roles and their inherent tensions;
- Identify and evaluate financing and sustainability models for State-based HIE projects;
- Determine which, if any, Federal programs could support more sustained funding mechanisms;
- Establish current directories of comparable projects that foster shared learning and development of common terminology e.g., MPI, RLS, data repositories;
- Gather consistent and sufficient detailed information on core project components and infrastructure development to support comprehensive and accurate information dissemination;
- Assist States and HIE projects with strategies to more effectively engage physicians; and
- Work with States to identify opportunities and conflicts across State-based projects and mechanisms for integrating within and across States—particularly as RHIOs emerge.

Appendix A

Research Methodology

Overview To support this study, Avalere Health conducted literature reviews, extensive web-based research, and examined a set of reports²⁶ with aggregated information on HIE projects across the country. Using State-based filters and certain exclusions, Avalere identified projects meeting the agreed-upon characterization of State HIE. Based on an environmental scan, Avalere identified eight State-based projects to represent a cross section of HIE activity. Avalere developed an interview guide and conducted interviews with representatives from each of the eight HIE projects to support further analysis and an in-depth review. The authors conducted informal interviews with a set of Federal decisionmakers to help inform the implications section of this paper. The environmental scan, interviews, and eight detailed case studies provide the basis for the report findings.

Sources and Inclusion Criteria In conducting the scan of HIE activity, Avalere gathered information for this report by surveying relevant literature, reviewing public aggregate sources including numerous online reports and Web sites, and conducting interviews with HIE project representatives and a set of Federal policymakers. Aggregate sources used in research include:

- Public Reports including eHI 2nd Annual Survey, AHIMA Survey on RHIOs, IDX and CHT report, and
- Foundation Web sites, such as Robert Wood Johnson Foundation, California Health Care Foundation, and Markle Foundation
- Federal agency Web sites, such as AHRQ, GAO, and HRSA
- State government Web sites, such as State Coverage Initiatives and State and Local Government on the Net
- Organization Web sites, such as eHI

To narrow the vast number of HIE-related projects and address the State focus of this project, Avalere applied the following “filter” criteria to all identified initiatives:

- 1) Did the project include State and/or Medicaid agency involvement through funding, program direction, or other means;
- 2) Did the project target patients Statewide or targets a large portion of patients across the State or in a specific area of the State; or
- 3) Did the project involve a Statewide Regional Health Information Organization (RHIO) or a RHIO-like construct with broad cross-collaboration and stakeholder involvement?

Avalere specifically excluded projects or initiatives that were contained solely within a single hospital or health system due to the absence of a broader community focus, as well as HIT projects that were primarily administrative or focused on reducing fraud and abuse, e.g., investments in States’ MMIS.

State involvement often translated either as direct involvement of the Department of Health or other State agency, or involvement of members from the Governor’s cabinet serving as decision-makers for the initiative. As for Medicaid involvement, Avalere specifically included projects where the State’s Medicaid agency was listed as a stakeholder in the HIE project.

In reviewing the research and specific resources, Avalere paid particular attention to projects highlighting HIT/HIE or State activity. Additionally, the authors searched Web sites for various technologies frequently found in these project including EHR, eRx, CDR, and CPOE.

²⁶ Center for Health Transformation (CHT) and IDX report; American Health Information Management Association (AHIMA), Association of Medical Directors of Information Systems (ADIMS), and Healthcare Informatics Regional Health Information Organization (RHIO) Survey; Foundation for eHealth Initiative Second Annual Survey of State, Regional, and Community-Based HIE Initiatives and Organization

Selection Criteria for Eight States In selecting State projects for this study, the authors sought to highlight a cross-section of States and projects. The following criteria, outlined at the beginning of the Case Study section, were considered when selecting these States:

- Progressive (e.g., more advanced or experienced)
- Innovative (e.g., demonstrated a novel approach or priority)
- Replicable (e.g., scalable project or initiative that was more narrowly focused and potentially easier for other States to implement)
- Geographically diverse (e.g., small, mid-size, and large States)
- Unique target populations (e.g., populations often not a focus of HIE projects-- LTC population).

Through the selection process, which was based on an initial understanding of the programs from available aggregate sources, Avalere sought to present: 1) a range of States that had both more and less experience in HIE exchange or HIT adoption broadly, 2) a mix of both small and large States and programs focused on urban and rural locations, and 3) projects that might be considered more easily “replicable” or serve as a ready model for other States in earlier stages of HIE and HIT adoption.

Research Limitations New HIE projects are being established on a regular basis and those already in place continue to progress. While Avalere used a variety of research techniques to obtain the information behind this report, much of the background research was from aggregate sources. The data from these resources had a number of limitations, including:

- The information is a “point in time” and quickly becomes outdated as HIE activities continue to evolve;
- The information is often self-reported and not subject to external review or validation. Additionally, characterizations of project activity may often reflect the broader goal (e.g., Statewide HIE implementation) versus providing a picture of the project’s current status (e.g., planning stage); and
- The sources include varied information and therefore it is oftentimes difficult to compare across the project activities (e.g., status, stakeholders, funders, timing, etc.).

State HIE activity continues to grow and Avalere’s characterization is only a snapshot of this activity. This study is not intended to be a comprehensive analysis of all HIE activity in the US, but rather showcase a meaningful cross-section of States and activities, present more comprehensive and accurate information on select HIE activities, and further the overall dialogue on planning and implementing HIE projects at the State, regional, and community levels.

Appendix B

Other Federal Activity

The Centers for Medicare and Medicaid Services The main CMS program focused on HIT in the States is Medicaid, the State-based entitlement program that funds services for low-income families and children. Medicaid's HIT focus has historically been the MMIS, which support claims processing and facilitates information retrieval for the State Medicaid programs. CMS believes that policy, business, and technological drivers over the past three decades have drastically reshaped the MMIS architecture, and accordingly, the Agency has begun to consider how the MMIS could be expanded to support broader Statewide HIE needs. To help rectify the different business and policy drivers that have led to an assortment of MMIS from State to State, CMS awarded a contract in 2002 to fund the Medicaid Information Technology Architecture (MITA) initiative (discussed below).

CMS' HIT focus has historically been in the context of Medicare program operations and pursuant to its regulatory responsibilities for HIPAA. CMS continues to foster HIT adoption through its regulations and demonstration projects. The Agency has also focused work on a set of HIT requirements and developments under the Medicare Modernization Act of 2003 (MMA) as well as more recent initiatives established under the CMS Office of Demonstrations.

In October 2005, CMS and the Office of the Inspector General (OIG) released two proposed rules to help facilitate the adoption of HIT and HIE nationwide. These rules outline proposed exceptions to the Stark rule and safe harbors under the anti-kickback statute that would permit the donation of items and services related to eRx and EHR technology.

Shortly thereafter, in November 2005, CMS released the final rule on eRx foundation standards for the Medicare Part D program. In this final rule, CMS issued a limited set of regulations which addressed the scope of the eRx program, requirements for Part D drug plan sponsors, regulatory exemptions, State preemption requirements, and a minimum set of foundation standards. It represents CMS' first step in an incremental approach to adopting final eRx standards, a process which will rely on a pilot program that will facilitate practical testing of these standards in States and local communities.

CMS has solicited public input on what role it and its wealth of data on Medicare beneficiaries should play in the development and use of personal health records (PHRs). In July 2005, the Agency issued a Request for Information (RFI) to assess what PHR functions are important to beneficiaries, if the Agency should provide some PHR services directly to beneficiaries, and the type of data it should make available to vendors. It is likely through this Federal interest, coupled with the direction of the Community, that PHRs will gain increasing traction and importance in the national HIT movement.

Healthcare Quality Demonstration Programs CMS announced in 2005 the nationwide expansion of The Doctor's Office Quality-Information Technology (DOQ-IT) pilot program, which was originally launched in 2003. DOQ-IT is designed to support the adoption and appropriate use of HIT in small- and medium- sized physician offices. Through this program, Quality Improvement Organizations (QIOs) support physician practices in selecting and implementing cost-effective HIT for their offices and improving overall quality of care. Additionally, DOQ-IT is intended to support provider-performance improvements by electronically reporting quality measures to the QIOs. CMS intends for the DOQ-IT program to increase physicians' overall use of HIT and thus improve the efficiency, clinical quality, and safety of care provided to Medicare beneficiaries.

Another CMS initiative that comprehensively uses HIT as a mechanism for supporting health care reform is the Medicare Health Care Quality Demonstration Program (MCHQ), mandated by Section 646 of the MMA. This demonstration is intended to develop, test, and disseminate major and multi-faceted improvements to the health care system. In addition to the potential for changing and improving the delivery of high quality

health care, this demonstration should increase efficiency and reduce the costs associated with Medicare Parts A, B, and C. AHRQ is also a partner in this demonstration and will facilitate learning among participants to help them identify ways to disseminate, replicate, and share their experiences across the health care community. With a primary goal of improved quality across the care continuum, this demonstration program may ultimately contain some of the most robust IT infrastructures being supported by Federal funding.

Medicaid Information Technology Architecture²⁷ The implementation of Medicaid benefits varies widely from State to State. While many people believe that this diversity has allowed States to customize their program to meet the varying needs of their populations, this lack of uniformity has also led to disparate systems for claims processing. As a result, information exchange across systems and State boundaries is hindered and information is siloed, making the States and the Federal government less able to coordinate care for Medicaid beneficiaries. In response to these challenges, CMS has aligned with ONC's goals for the NHII to launch the MITA initiative.

MITA is intended to foster integrated business and information technology transformation across the Medicaid enterprise in order to improve the administration of the Medicaid program. While the MITA transformation is on a five to ten year timeframe, CMS reports having collaborated with over 15 States through voluntary, early adopter relationships on specific State projects. Of note, none of the HIE projects interviewed have worked with CMS on MITA. However, a subset of projects that were aware of MITA indicated that cross collaboration between MITA and the HIE was only in the planning stages.

Medicaid Waivers for Home and Community Based Services (HCBS) Passed in 1981, HCBS legislation provided a vehicle for States to offer additional services not otherwise available through their Medicaid programs to serve people in their own homes and communities. These waivers afford States the flexibility to develop and implement creative alternatives to placing Medicaid-eligible individuals in hospitals, nursing facilities, or intermediate care facilities. The flexibility afforded by these waivers is how some States have been able to engage in HIT pilots or projects to support remote monitoring, telemedicine, or HIE with this targeted population. Moreover, States are beginning to look to HIT infrastructure to facilitate better monitoring and support for these waiver participants.

The Centers for Disease Control and Prevention One broad initiative at CDC, the Public Health Information Network (PHIN) Initiative, is intended to provide integrated public health information systems to counter national civilian public health threats. This initiative includes surveillance systems to monitor disease outbreaks and data exchange applications to facilitate communication amongst public health officials. For public health emergencies, the ability for real-time HIE between providers and public health agencies is critical to detect and respond to naturally occurring and bioterrorist spawned disease outbreaks. CDC is looking to implement surveillance, communications, and diagnostic systems that will use HIT to help secure the nation's public health. However, these systems will be largely dependent upon a national infrastructure network, which has yet to be built. Also important to these initiatives are the standards development and harmonization processes. To that end, a major component of the PHIN is the National Electronic Disease Surveillance System (NEDSS). NEDSS is an initiative that promotes the use of data and information system standards to advance the development of efficient, integrated, and interoperable surveillance systems at Federal, State, and local levels.

The Federal government is also involved in the advancement of HIE and HIT in the States through the distribution of grants, notably through AHRQ and HRSA.

²⁷ More information on MITA is available at <http://www.cms.hhs.gov/MedicaidInfoTechArch/>

Other Federal HIT Grants to States

HRSA The Health Resources and Services Administration (HRSA) established the Office for the Advancement of Telehealth (OAT) to serve as a leader in telehealth, a focal point for HRSA's telehealth activities and a catalyst for wider adoption of advanced technologies in the provision of health care services and education. Through its legislated authority, OAT administers the Telehealth Network Grant Program, which provides grants to develop telehealth network projects in rural and medically underserved areas. The goals of this grant program are to (a) expand access, coordinate, and improve the quality of health care services; (b) improve and expand the training of health care providers; and (c) expand and improve the quality of health information available to health care providers, patients and their families. In short, the primary objective of the Telehealth Network Grant Program is to "help communities build the human, technical, and financial capacity to develop sustainable telehealth programs and networks."

The eHI Foundation is a prominent recipient of a large OAT grant. With HRSA funding, eHI launched the Connecting Communities for Better Health (CCBH) program, through which it has provided a number of grants to communities across the country to foster the planning, development, and implementation of HIE projects. eHI develops and disseminates tools and resources, and provides seed funding and technical support to help State, regional, and community-based HIE projects navigate the organizational, legal, technical, and financial challenges of mobilizing data to support health and health care goals.

NLM The National Library of Medicine (NLM) provides grant support to health-related institutions and organizations for projects to plan, design, test, and deploy systems and techniques for integrating data, information and knowledge resources into a comprehensive networked information management system. These are organizations working to build Integrated Advanced Information Management Systems (IAIMS). IAIMS are computer networks that link and relate databases containing published biomedical knowledge to individual and institutional databases, both within and external to a given institution. The goal of IAIMS is to establish a comprehensive and convenient information management system that facilitates the transformation of knowledge into action and bridges the divide between clinical information and clinical practice settings (e.g., between health care settings and research institutions).

Of particular interest to NLM are projects that focus on information to guide learning and decisions; standardized information systems that drive interoperable information exchange; and digital libraries. NLM is also particularly interested in the area of clinical informatics and how technology can bring value to the delivery of health care, the management of health information, and the support of informed decision making by consumers, patients, health care providers, and health care administrators.

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Glossary

ADEs	adverse drug events
ADIMS	Automated Drug Information Management System
AHCA	American Health Care Association
AHIMA	American Health Information Management Association
AHRQ	Agency for Healthcare Research and Quality
AHCCCS	Arizona Health Care Cost Containment System
BHS	Behavioral Health System
BTE	Bridges to Excellence
CCBH	Connecting Communities for Better Health
CCHIT	Certification Commission for Healthcare Information Technology
CCR	continuity of care record
CDC	Centers for Disease Control and Prevention
CDR	central data repository
CHF	congestive heart failure
CHIDS	Center for Health Information and Decision Systems
CHIN	Community Health Information Network
CHCF	California HealthCare Foundation
CHT	Center for Health Transformation
CMS	Centers for Medicare and Medicaid Services
The Community	The American Health Information Community
CPOE	computerized physician order entry
DOH	Department of Health
DOQ-IT	Doctor's Office Quality-Information Technology
EDs	emergency departments
EHR	electronic health record
eHI	eHealth Initiative
eLab	electronic laboratory reporting
eRx	electronic prescribing
FHIN	Florida Health Information Network
F-SHRP	Federal-State Health Reform Partnership
GAO	General Accounting Office

HBHC	Hawaii Business Health Council
HCBS	Medicaid waivers for home and community based services
HEALTH	Rhode Island Department of Health
HHS	Health and Human Services
HIE	health information exchange
HIMSS	Health Information Management Systems Society
HIPA	Hawaii Independent Physicians Association
HIPAA	Health Insurance Portability and Accountability Act of 1996
HISPC	Health Information Security and Privacy Collaboration
HIT	health information technology
HMA	Hawaii Medical Association
HQI	Healthcare Quality Initiative
HRSA	Health Resources and Services Administration
HSAG	Health Services Advisory Group
IAIMS	Integrated Advanced Information Managements Systems
ICU	intensive care unit
IDN	integrated delivery network
IT	information technology
LTC	long-term care
MCHQ	Medicare Health Care Quality Demonstration Program
MITA	Medicaid Information Technology Architecture
MMA	Medicare Modernization Act of 2003
MMIS	Medicaid Management Information System
MPI	master patient index
NCHICA	North Carolina Healthcare Information and Communications Alliance
NEDSS	National Electronic Disease Surveillance System
NGA	National Governor's Association
NHII	National Health Information Infrastructure
NHIN	Nationwide Health Information Network
NLM	National Library of Medicine
OAT	Office for the Advancement of Telehealth
OIG	Office of the Inspector General

ONC	Office of the National Coordinator
PAiRS	Provider Access to Immunization Registry Securely
PBM	pharmacy benefit manager
PCP	primary care physician
PHIN	Public Health Information Network
PHR	personal health record
POC	point of care
QHA	Quality Healthcare Alliance
QIO	Quality Improvement Organization
RFA	request for applications
RFI	request for information
RFP	request for proposals
RHIO	Regional Health Information Organization
RIQI	Rhode Island Quality Institute
RLS	record locator service
ROI	return on investment
THIQIT	Transforming Healthcare Quality through Information Technology
UHIN	Utah Health Information Network
UPIN	unique patient identifier number
VPN	virtual private network
WWP	Worksite Wellness Program

Technical Dictionary

This glossary is provided as simplified background for less technical readers. These are not formal or standard definitions. The authors observed throughout this project that there is not a standard HIT terminology consistently or readily understood throughout the industry.

CDR (Central data repository)

A comprehensive database designed to modernize and streamline how information is collected, validated, and distributed. A CDR provides a central location where data can be stored and retrieved and is used to maintain and manage data collected from clinical service encounters across a variety of care locations (e.g., hospitals, clinics). CDRs are often Internet-based, but can also be located within a mainframe computer (defined below).

Central server

A computing configuration that houses data and applications that can be accessed by various points across a computer network.

Centralized architecture

In a centralized architecture, all data resides in one locale, generally a central server. This approach offers security and system management benefits, although disadvantages with this approach include concerns about “data ownership” and space requirements to support this architecture.

Federated architecture

A network of individual enterprises that are connected to share data. The information resides and is maintained locally within individual entities, but is linked together and can be accessed globally across the network. This is also referred to as a decentralized architecture.

IDN (Integrated delivery network)

A single organization or a group of affiliated organizations that typically supports a broad range of services across the health care continuum. An IDN may include a cross-section of providers including physician groups, hospitals, long-term care facilities, and rehabilitation centers. An IDN often takes on the financial risk of insuring some of the population it treats.

MMIS (Medicaid Management Information System)

An integrated group of computer processing operations designed to manage and control Title XIX (Medicaid) program and administrative costs; service to recipients, providers, and inquiries; operations of claims control and computer capabilities; and management reporting.²⁸

MITA (Medicaid Information Technology Architecture)

A national framework to support improved systems development and health care management for the Medicaid enterprise. The overall goal of the MITA project is to facilitate an improved process for design and implementation of systems that improve quality and efficiency in health care delivery, which in turn will improve beneficiary and population outcomes. MITA is also intended to foster integrated business and IT transformation across the Medicaid enterprise to improve the administration of the Medicaid program.²⁹

²⁸ More information on MMIS is available at <http://www.cms.hhs.gov/MMIS/>

²⁹ More information on MITA is available at <http://www.cms.hhs.gov/MedicaidInfoTechArch/>

MPI (Master patient index)

A computer-based system that links patient information across a variety of health care settings. Due to variation in names and the common problem of duplication (e.g., multiple John Does), a MPI uses a range of data and matching algorithms to ensure unique individual identification. An assigned unique identifier facilitates access to patient-specific clinical information at all points of care.

Mainframe Computer

A large, high-performance computer connected to multiple users.

NHIN (Nationwide Health Information Network)

NHIN is the integrated technical infrastructure that will link health care information systems across the U.S. to allow patients, providers, hospitals, public health agencies, and other authorized users to share real-time clinical information under stringent security, privacy, and other protections. The NHIN is described in greater detail in ONC's Framework for Strategic Action, available at:

<http://www.hhs.gov/healthit/strategicfrmwk.html>.

RLS (Record locator service)

A RLS provides information about *where* patient health information is located and where the patient has received care (e.g., physician's office) but does not contain the actual patient information itself.

Security standards

Security standards, consistent with HIPAA, are the policies, processes, physical and organizational safeguards, and technical requirements set to address availability, integrity, and confidentiality of individually identifiable health information.

Portal

An entry point or gateway for users, oftentimes through the Internet or Intranet. Private sector examples include AOL and Yahoo.

Web services architecture

Internet-enabled enterprise applications that use open Internet protocols as the bases for system design to ensure interoperability.

Web services interface

The means by which applications are accessible for the integration of multiple applications across multiple platforms, Web sites, or information sources.

VPN (virtual private network)

A technology platform that establishes a private or secure network connection within a public network. The VPN can be used within a Local Area Network and/or over public networks such as the Internet.

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ADVANCE for Health Information Professionals Web site. <http://health-information.advanceweb.com/>

Agency for Healthcare Research and Quality (AHRQ) National Resource Center for HIT Web site. <http://healthit.ahrq.gov>

Alliance for Healthcare Reform Web site. <http://www.allhealth.org/>

American Health Care Association (AHCA) Web site. <http://www.ahca.org/>

American Health Information Management Association Web site. <http://www.ahima.org/>

The Brookings Institution Web site. <http://www.brookings.org/>

California HealthCare Foundation Web site. <http://www.chcf.org/>

iHealthBeat Web site. <http://www.ihealthbeat.org/>

Center for Health Transformation Web site. <http://www.healthtransformation.net>

Centers for Medicare and Medicaid Services (CMS) Web site. <http://www.cms.hhs.gov/>

The Commonwealth Fund Web site. <http://www.cmwf.org>

eHealth Initiative Web site. <http://www.ehealthinitiative.org/>

Connecting Communities for Better Health (CCBH) Resource Center. <http://ccbh.ehealthinitiative.org/communities/default.aspx>

eHealth Initiative State and Regional Health Information Technology Summit Initiative Web site. <http://www.ehealthinitiative.org/initiatives/programs/aboutStatesummit.aspx>

Government Accountability Office (GAO) Web site. <http://www.gao.gov/>

Healthcare Information and Management Systems Society (HIMSS) Web site. <http://www.himss.org>

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HIT Dashboard Web site. <http://www.hitdashboard.com/>

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National Association of State Information Executives Web site. <http://www.nascio.org/>

National Association of State Medicaid Directors Web site. <http://www.nasmd.org/>

National Conference of State Legislatures Web site. <http://www.ncsl.org/>

National Governors Association Web site. <http://www.nga.org/>

Office of the National Coordinator for Health Information Technology (ONC) Web site.
<http://www.hhs.gov/healthit/>

Public Health Informatics Institute Web site. <http://www.phii.org/>

RAND Corporation Web site. <http://www.rand.org/>

The Robert Wood Johnson Foundation Web site. <http://www.rwjf.org>

Western Governors' Association Web site. <http://www.westgov.org/>

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