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Large Scale Health Information Exchange: Implementation Experiences from Five States

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Abstract

There is widespread consensus that Health Information Exchange, the electronic sharing of patients' health information between delivery settings, is critical to improving the quality and efficiency of patient care. The United States has had limited success in establishing broad-based HIE. To address these issues, the federal government funded the State Health Information Exchange Cooperative Agreement Program. An in-depth qualitative study was conducted, consisting of site visits and semi-structured discussions with 105 respondents in 5 states to understand early HIE implementation experiences. Results show the last two years have seen unprecedented growth in HIE infrastructure. Key factors such as maturity of HIE at baseline and healthcare market characteristics have shaped governance models and technical infrastructures. Early focus on stakeholder value proposition and sustainability planning is critical for long-term success. States continue to face numerous challenges in converting stakeholder support into financial commitment and real-time exchange of health information. We discuss the key issues states faced in attempting to realize broad-based HIE and offer insights that may assist other states.

Keywords:

Health Information Exchange, Electronic Health Records, Direct, HITECH Act, Policy Implications, Health Care Reform.

Introduction

In response to the realities of an aging nation, ballooning health care costs, and calls for higher quality patient-centric care, agencies across the Department of Health and Human Services have committed to bring new levels of quality, efficiency, safety, and patient-centric care to the U.S. health care system. Technology is widely acknowledged to be the primary vehicle for achieving these goals. [1]

The Health Information and Technology (HITECH) provisions of the American Reinvestment and Recovery Act (ARRA) in 2009, and the recent Federal Health IT Strategic Plan codifies these desires and introduces a framework to ensure the use and enhance the capabilities of health information technology between 2011 and 2015. A central component of this strategy is the exchange of health information (HIE) among providers across all care settings. [2]

Efforts to establish HIE services have been underway in the United States for over twenty years. These efforts have had limited success in a constantly evolving market in which demand has shifted from one stakeholder group to another, and one HIE solution to another. Moreover, challenges surrounding technology costs, interoperability, and stakeholder engagement and support exert pressures that many budding HIE initiatives cannot withstand. [3], [4]

In 2009, the Office of the National Coordinator for Health Information Technology (ONC) created the State HIE Cooperative Agreement Program ("the Program") and announced the availability of $564 million for states and territories to enable HIE. [5] The purpose of the Program, authorized by section 3013 of the Public Health Services Act (PHSA) and amended by the Health Information Technology for Economic and Clinical Health Act (HITECH Act), is to "facilitate and expand the secure, electronic movement and use of health information among organizations according to nationally recognized standards." [6] The foundational notion behind the program is that the timely sharing of electronic health information can improve health care quality, efficiency, and safety. It does so by ensuring health providers have access to comprehensive clinical information that allows them to provide better patient care. It also vastly expands the amount and quality of health-related data, which can improve public health programs and clinical research, and support quality, efficiency, and safety improvements. [7] ONC is at the helm of this project, establishing the policies and standards to facilitate the data exchange, query, and aggregation necessary to achieve the secure movement and use of health information. [8]

Methods

The primary objectives of this study are to: 1) Assess the experience of states in establishing governance structures, technical services to enable health information exchange, and privacy and security frameworks; 2) Assess stakeholder priorities, current use, and anticipated need for information exchange; 3) Identify common enablers, barriers, and challenges states encounter during implementation; and 4) Collect and characterize lessons learned during implementation.

Five states were selected for evaluation based on their levels of progress enabling statewide HIE using different methods and in diverse local environments. The five states varied in population size, geographic makeup (i.e., rural versus urban areas), HIE technical models, and their adopted governance structures. Between November 29, 2011 and March 21, 2012, a qualitative in-depth examination was conducted. This consisted of site visits, focus groups with large and small practice physicians, and semi-structured interviews held with a variety of stakeholders, shown below in Table 1.

Table1- Interview Respondents by Stakeholder Type

Respondent Type	Total
Large health systems representatives ambulatory-care providers	22
Provider associations	15
State Designated Entity (SDE) Directors and support staff	15
State Health Information Technology (HIT) Coordinators and support staff	11
Other respondents, as relevant for each state (Quality Organizations, Indian Health Service, Employer Organizations, Advisory Broad Members)	8
Medicaid personnel	6
Regional Extension Center leads	6
State Public Health Office personnel	6
Health Information Organization representatives	5
Vendors (EHR, HIE, Health Information Service Provider (HISP) for Direct)	5
Consumer advocates	4
Lab representatives	2
Total Respondents	**105**

Interviews were transcribed and coded based on key interview themes: maturity of HIE prior to the HITECH Act, governance structure, technical strategies, respondent-identified successes, and primary challenges. The coding also allowed us to identify experiences unique to each state, as well as crosscutting themes and important factors that influence a state's choice of technical model. This information was then used to create a detailed profile of each state and its key elements.

Results

This paper briefly discusses the key factors that affect each state's planning and strategy, and focuses on the implementation experience. Table 2 provides an overview of each state and their approach.

Table 2- State Overview and Strategic Approach

State	Population Size	Funding Amount	Technical Approach
Maine	1,328,361	$6,599,401	Heavy infrastructure
Nebraska	1,826,341	$6,837,180	Heavy Infrastructure
Texas	25,145,561	$28,810,208	Thin layer, local grant program
Washington State	6,724,540	$11,300,000	Thin layer with hub, translation services
Wisconsin	5,686,986	$9,441,000	Thin layer network of networks

Factors influencing state strategy and planning activities. In each state, pre-HITECH activities played an important role. All five states had health IT initiatives underway prior to receiving ONC funding, which contributed substantially to the states' readiness and their subsequent implementation progress. In some cases, these initiatives consisted of pilot and demonstration projects, while in others policy levers paved the way for state-led services. On the whole, stakeholders report that previous HIE efforts in their states facilitated collaboration and established trust between state officials and other stakeholders that has been integral to states' success. It also created a knowledge base and a "culture" that paved the way for interest in state-led HIE activities.

Characteristics of the local health care market also influenced each state's implementation strategy to enable statewide HIE. We identified 5 factors that appear to influence states towards particular technical models: geography, large health systems, physician practice size, independent versus health system-owned and affiliated providers, and the role of technology vendors. 1) *Geography* (urban vs. rural) and population characteristics. In urban centers like cities in Washington and Wisconsin providers often described working at multiple locations—in different hospitals or at multiple offices of the same practice—and seeing patients with providers and specialists at different locations and not necessarily in the same health systems. In this environment, exchange of health information tends to occur in a more decentralized way, leveraging mechanisms offered by local providers. In contrast, patients in rural states often rely on small regional care centers for primary care and must travel to see multiple providers for major health concerns, which can make proper care coordination a challenge. In this environment, exchange of health information and data storage in a central repository can allow providers to collect otherwise diffuse health records to provide better care and coordination. *2) The role of large health systems*. Large health systems generally have the technical infrastructure to support EHRs and HIE, they often deliver the bulk of health services in a local market, which may create competitive pressures in favor of HIE, and they appear to be supporting non-state led options for HIE, including private networks and affiliations with providers in their community. Although the literature is limited on this subject, one study found that less competitive marketplaces tend to have greater hospital participation in a regional Health Information Exchange Organization (HIO), an entity that governs and oversees the exchange of information among different healthcare providers. [9] The same study found that non-profit hospitals and hospitals with a large market share are more likely to participate in regional HIOs than for-profit hospitals. This is true in Maine where large health care delivery systems and IDNs are exploring alternatives to state-led HIE services. These health systems are pursuing private HIE because it allows them greater control of the information and how it is exchanged than a public or state-enabled HIO. According to a 2011 KLAS performance report, between 2010 and 2011 the number of live public HIOs in the country grew from 37 to 67 HIOs, while the number of private HIE initiatives increased from 52 to 160. [10] *3) The presence of small versus large practices*. In general larger practices tend to have greater resources to invest in EHRs and HIE. Large physician practices often drive EHR adoption and HIE in a similar way as large health systems: their size and affiliations necessitate adoption and they have enough members for their decisions (e.g., in vendors, service types, and whether to enable state-led or private HIE) to influence the market. *4) The presence of independent versus health system-owned and affiliated providers.* When practices are part of a larger corporate entity they have options to exchange information by leveraging the infrastructure of the corporate entity, which allows the practice a lower cost of entry. As a result, states with large numbers of affiliated providers tend to have higher EHR adoption, which

paves the way for information exchange. *5) The existence and influence of technology vendors.* The services that vendors offer in a local marketplace inevitably influence the evolution of that marketplace. EHR vendors currently offer a range of HIE solutions that give providers options outside of local/regional HIOs or state-led services. As a result, some states are focusing on providing services that fill gaps in the vendors' offerings.

State implementation experiences. For the Program, states were encouraged to focus on "developing statewide policy, governance, technical infrastructure and business practices needed to support the delivery of HIE services." The funding announcement required states to submit and receive approval for their Strategic and Operational Plans, which described their overall approach to enabling HIE. The release of funds to states was contingent on receiving plan approval. States were allowed significant latitude in determining the most appropriate approach based on their individual needs.

Technical approaches leverage existing infrastructure. In most cases, states are responding to a dual need of enabling information exchange that allows providers to improve patient care and coordination, its quality, and its efficiency, while also complying with meaningful use requirements under the federal EHR Incentive Program (i.e., lab exchange, e-prescribing, and exchanging clinical care documents). They have pursued different approaches to doing so. In some cases, the state or an entity designated by the state to support HIE opted to build HIE services (e.g., Wisconsin, Maine, Washington State, and Nebraska). In other cases, the state has opted to leverage existing HIO activities within the state, as evidenced by the model adopted by Texas.

The five states selected one of two technical models: a "thin layer" model with services based on light infrastructure (Texas, Washington and Wisconsin), or a heavy infrastructure model (Nebraska and Maine) with features such as a central repository. In general, the thin layer model refers to light infrastructure that primarily supports messaging and directories, but lacks a central data repository. In addition, a number of states are pursuing Directed messaging. Direct is a set of standards, policies, and services to transport health information point-to-point through a secure, fast, and inexpensive "push" model, thereby creating an additional method for health information exchange. [11] Discussions with stakeholders identified several advantages to the thin layer approach such as cost savings that stems from the lack of a central repository, which can be expensive and time consuming to build and maintain; fewer privacy concerns associated with providing HIE services; and greater flexibility as states can respond quickly to market changes and be quick to market because the time required to enable these services is vastly reduced. States that invest in heavy infrastructure centralize the storage of their state data and, in doing so, may create a rich data source for analysis. Centralized records can help highlight existing gaps in public health, quality, and outcomes data, which may be useful for identifying trends and for launching or informing statewide improvement initiatives.

Leadership and governance models. Prior to the Program, many HIE initiatives were led by a single entity that controlled both policy and technology. The single lead entity was also the dominant model in early statewide HIE efforts, such as the Delaware Health Information Network (DHIN), the first statewide HIO. [11] Under the current program, different entities often play governance and/or technical operator roles and the roles of these entities are likely to evolve over time, decoupling the policy and technology roles. This decoupling is far from universal (e.g., in South Carolina and South Dakota the state is responsible for both the governance and technical architecture of statewide HIE). But the five states profiled in this report all chose to decouple governance and technical functions in their governance approaches, which stakeholders in these states generally regard as an effective strategy.

Empowering a non-state lead organization to procure and manage the HIE technical infrastructure benefits both the state and the HIE Program. For example, in times of financial hardship, when states are experiencing budget cuts, a non-governmental lead technical organization may pursue other business lines for revenue to maintain operations. The decoupling of governance and technical leadership roles also allows entities to "play to their strengths." Using this approach, the state provides guidance based on the policy and legislative environment, while an SDE provides technical expertise and market savvy, and has the ability as a private entity to make decisions more swiftly than the state.

Individual choice and consent. ONC indicated states should ensure that individuals have "meaningful choice regarding whether their individual identifiable health information (IIHI) may be exchanged through the HIE entity" when HIE entities store, assemble, or aggregate IIHI. ONC also clarified that patient choice is not required beyond existing state law when HIE entities serve as conduits for Directed messaging.[13] With the exception of Washington State, four out of five states are enabling Direct services as part or all of their service offerings. States that are enabling or plan to enable additional query-based exchange services, meaning that providers have the ability to search and retrieve stored health information, must pursue consent policies to govern these actions.

Table 3- State Consent Models

State	Consent Model	Central Repository
Maine	Opt-out with exceptions	Yes
Nebraska	Opt-out with exceptions	Yes
Texas	None	No
Washington	None	No
Wisconsin	Pursuing harmonization with HIPAA (opt-out)	No

Of the five states included in the case studies, two states (Maine and Nebraska) are pursuing an opt-out model with opt-in for sensitive health information; two states (Texas and Washington) do not have a state level consent policy; and Wisconsin is planning harmonizes state law with HIPAA so that no additional consent is required and patient health information is automatically included without an option for patients to opt out. While consent does not present an issue in Washington because the state does not store data, Texas did confront consent issues even in the absence of state-level data storage. In Texas, local HIOs are all pursuing different approaches and are concerned this may present issues for HIO-to-HIO exchange. Nebraska and Maine, both of which main-

tain central repositories, have adopted opt-out with exception consent models. In both states, stakeholders report the opt-out model has encouraged patient participation in exchange.

Sustainability. Sustainability models are a critical element to ensuring the long term success of state-led HIE activities that remain in the nascent stages in most states. All five case study states currently rely on subscription fees paid by their users, and some are using their remaining ONC funds to operate until other sources of revenue can be determined. States that have recruited large health systems and/or payers for the bulk of funding describe the pressure to provide value for these stakeholders to ensure their continued participation and the concern that delays in the implementation process may result in the waning interest of these entities. Similarly, these entities have expressed desire to participate in the success of statewide HIE but a desire to see a return on investments in the near future.

Key enablers to HIE. In reviewing cross-cutting themes, we identified the following key enablers to HIE: 1) Incentives and grants like MU and the State HIE Program have done much to help states and providers defray the cost of investing in infrastructure; 2) Although it is not universal across the State HIE program, all five of our case study states chose to decouple their policy and technical functions. Dividing responsibilities allows entities to play to their strengths: states navigate the legislative and policy environment, while the technical entity can employ its technical and market savvy to guiding implementation; 3) Responding to local market needs are a combination of services catering to stakeholder needs, while also complying with meaningful use requirements; 4) Coordination and communication is key to stakeholder buy-in and strategic partnerships are critical in these endeavors; and 5) Leveraging existing investments by assisting existing regional networks and supporting new ones targeting providers without HIE services.

Challenges. Stakeholders also identified key areas that continue to pose significant challenges to broad-scale HIE. Firstly, cost and sustainability were universally acknowledged as a primary challenge to HIE. Regardless of state, local market, or technical approach, concerns were expressed over the cost of infrastructure investment and the costs of initiation and maintenance of services and technology. Furthermore, the costs of interfaces and lack of support for providers are recurrent issues in four out of the five states. Stakeholders reported that services, particularly EHR interfaces, are too expensive to enable and vendor support is absent or insufficient to justify the purchase and use of services.

Stakeholders viewed low provider awareness of state-led HIE initiatives as an important challenge to adoption and one that is tied to uptake and sustainability. Although providers are familiar with different types of exchange, such as sending prescriptions and radiology reports electronically, they are less likely to view these individual activities under the larger umbrella of "statewide HIE services" or the state-led HIE Program, particularly if they are small providers. Rather, in many cases, small providers have low awareness of state-level policy and technical efforts, and low awareness of HIOs.

Engaging large health systems in state-led HIE was both a principal goal and a practical challenge among the states. Overall, other states were successful in gaining interest from large health systems but struggled to varying extents in convincing them to participate. For many health systems, the business case for participating in broad-based HIE remains elusive.

The evolution of the healthcare delivery market was a recurrent, but not a universal concern. Currently, there is increasing consolidation in the market: independent providers are affiliating with hospitals or joining larger practices and many EHR/HIE vendors now offer a range of HIE functions outside of state services. Expansion of private HIE is a growing concern for states and regional networks that have made investments in heavy infrastructure and fear their investments may become duplicative and/or unnecessary.

Stakeholders in some states reflected on whether it is in the interest of vendors to create interoperable systems, in spite of user demands for interoperability. For example, Washington stakeholders reported that the major EHR vendors in the state do not seem to provide truly interoperable systems, in spite of what is promised when providers purchase services. While these vendors may support interoperability between providers who have a similar EHR platforms, exchanging information with providers on different EHR platforms remains a challenge. Another common issue raised was the difficulty of exchanging clinical care summary documents between different provider EHRs. Even though EHR vendors are supporting the clinical care document (CCD) standard, the implementation of the standard varies between different vendors. Consequently, clinical care summary documents are exchanged as PDFs or text and not as structured data, complicating integration into some EHRs.

Conclusions

The past two years of the State HIE Cooperative Agreement has witnessed unprecedented growth and development in the health information technology infrastructure of the nation as well as broader changes in the healthcare delivery system. While most states are still in the earlier stages of development of their HIE programs, these five states have surged ahead into the implementation phase of their plans.

These states will face new challenges during the implementation phase as they are tasked with converting stakeholder support into financial commitment and real-time exchange of health information. Both the financial commitment and the actual exchange of clinical data pose substantial challenges. States must also enable services that address both meaningful use and market needs in their service offerings. This effort will be complicated by the complexity and evolution of the health care market, including expansion of the market-based solutions offered by vendors, and the growth of and competition from private HIE may create islands of exchange that potentially threaten more broad-based HIE activities. States will have a critical role to play in ensuring hospital systems and private HIE initiatives are willing to share at least the key data with providers outside their private networks, and with the state for quality monitoring and potentially comparative effectiveness research purposes.

Given the significant concerns about sustainability and who will pay for state-offered services in the long term, it may also prove beneficial to ensure that states have assistance, either from state or national informational resources, in developing both sustainability plans and contingency plans.

The case studies presented here, while not representative of all state-enabled HIE efforts, provide important insights into some of the key issues faced in attempting to realize broad-scale HIE and the experiences of these five states have the potential to provide important insights that may assist other states engaged in exchange activities.

Given all five of these states had a prior history of HIE points to a potentially difficult road ahead for states that have started more recently. However, there is reason to believe that other states can potentially make up ground with the lessons learned from early state efforts and herein lays some key policy recommendations. First, states should focus on governance and establishing the conditions for HIE, such as stakeholder involvement and provider awareness, regardless of whether or not they plan to directly provide HIE services and infrastructure. Communicating the value of HIE is critical. Therefore, a second key lesson is that states should harness provider interest in new care models, such as Accountable Care Organizations and Patient-Centered Medical Homes, to explain the role of HIE and providers' need to track the care of individual patients across multiple clinical sites. Third, states that are recent adopters can start laying the groundwork for solving long-term challenges, such as sustainability, by not only demonstrating the value of HIE but communicating the need for financial commitments from providers, at least in the long-run.

In conclusion, the close examination of these early adopters has taught us lessons not only for these states, but also for states that are to follow. Learning from early adopters can help all states with burgeoning programs or new interest benefit from the successes and sidestep some of the challenges that are inherent in building an HIE program.

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