

Data Governance - Deriving Value from Informational Assets

Chapter 8: Case Study: State Level Governance of Health Information Exchange¹

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Introduction

One of the major revolutions taking place in health care in the United States is the move from paper to electronic records in physicians' offices and hospitals across the country. This is a transformation that is more than just adopting the use of a computer and electronic health record software to replace the paper prescription pad and hand written notes. It is a fundamental change from inaccessible, office-bound paper documents to electronic records in a database that can be queried, summarized and used to track patient care. The electronic record increases accessibility to a patient's health information among office staff and physicians, benefitting administrative efficiency. Having the data in electronic format means that it can be sent electronically to another physician any time a patient is referred or transferred for care, bypassing the paper-based facsimile machine for the electronic exchange of records. This ability to exchange records electronically is the key to the transformation of patient care.

Implementing an electronic health record software system comes with associated expenses that include financial capitalization, technical training and practice down time while the system is installed and learned. Adoption has been slow among American physicians because of these costs, but it is taking place inexorably due to government incentives and market pressures. Once the physician's office is fully electronic, then the potential to connect to a health information exchange becomes possible. Health information exchanges have been emerging over the past decade as the principal means to provide for the bi-directional transfer of health records between physicians. The step up to a health information exchange, though, brings the physician out of his or her office into a community of physicians who can now access the same records for the coordination of patient care.

Values of HIE Governance

Moving from a single point of care to coordinated points of care requires managing multiple partners and often divergent perspectives, all of whom are connected through the electronic exchange of health information. So the development of the health information exchange brings with it the need to create an effective form of governance to manage the community of health care participants who are connected within the exchange network. These participants may have diverse or competing interests, dissimilar needs for data, unique requirements for the practice of medicine and different technical capabilities. To make this all work at a community level, a governance group needs to be created, preferably a trusted body of members from the health care community who can address competing interests and craft a consensus for the rules of exchange among participants in the health information exchange. The consensus-building and leadership

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values that a trusted, neutral group of people can bring to the governance of health information exchange are essential for its success.

The following discussion looks at the important issues in developing a governing organization for health information exchange and addresses the value a governing board brings to the exchange of health data. All health information exchange entails data access, data sharing and the authorizations required to share protected health information among physicians. The exchange of medical records brings with it potential liabilities that must be addressed and controls must be put in place to limit who has access to the records. This role is best undertaken by a governance body that has the ability to bring a diverse group of health care stakeholders to the table and to create trust relationships among them. Herein lies the value of good governance. The governance organization must function as a neutral body to convene stakeholders, to work out the rules for data-sharing activities, to establish business sustainability and to hold all participants accountable for their responsibilities for sharing health information. Only through this deliberative method of building trust, agreement and accountability for sharing data will a health care community lower its barriers to exchanging health records.

Case Study: State-Level Governance of Health Information Exchange

The steady development of community-based health information exchange was disrupted in 2009 when the passage of the American Recovery and Reinvestment Act altered the health information technology landscape in the United States (<http://www.gpo.gov/fdsys/pkg/GILLS-111hr1enr/pdf/BILLS-111hr1enr.pdf>, p. 116). The law specifically targeted building a national health information exchange infrastructure to support the creation of a Nationwide Health Information Network. The Office of the National Coordinator for Health Information Technology was authorized to develop a broad set of strategies to drive the adoption of electronic health records systems, create interoperability among them and foster the exchange of medical records electronically. Funds were allocated for paying incentives to doctors to adopt electronic health records and to make them interoperable through the construction of state-level health information exchange infrastructures.

A significant feature of the American Recovery and Reinvestment Act created state-designated entities that would become the recipients of federal funding for health information exchange and would act as the de facto governing boards of the new state-level infrastructure. With the passage of this Act, all 50 states and seven territories of the United States were pulled into facing the realities of constructing a health information exchange infrastructure and dealing with the issues of the governing health information exchanges. Placing governance responsibilities on the state-designated entities made them responsible for convening stakeholders statewide, crafting consensus among them and developing statewide policies for data-sharing. Their challenge was to implement the lessons learned from a decade of health information exchange governance attempts at the local level.

The following discussion moves from consideration of the major values of governance for community health information exchange to the challenges of implementing state-level governance organizations. The creation of the state-designated entities, and the efforts of state governments to craft the right balance between public and private sector control through an appropriate governance structure are examined. The case study considers how the important governance principles that were developed at the community level are translated into the national and state approaches to governance following the passage of the American Recovery and

Reinvestment Act.

Background to the Development of State-Level Health Information Exchange

Technical Background to Health Information Exchange

Health information exchange (HIE) is a telecommunication-based solution that enables medical record sharing among physicians, hospitals, clinics and other provider organizations. Health information exchange (HIE) is often used as both a verb and a noun. As a verb it refers to the electronic exchange of health information among providers and across health care organizations. As a noun it refers to an organization that facilitates the exchange of health information. The HIE (as a noun) integrates records from a wide variety of health care sources and presents them in a longitudinal, integrated view for the treating physician. The value of HIE lies in the coordination of patient care among physicians, hospitals and other health care facilities. It allows access to records from participants such as laboratories, pharmacy benefit networks, radiology or digital imaging facilities, health plans and electronic health record systems and ensures the secure and timely delivery of records for patient transitions of care.

State-level HIEs are being built across the country to leverage the implementation of electronic health record (EHR) systems in hospitals, clinics and physicians' offices and connect them to HIE networks to access patient records from other health care participants. Federally-funded state-designated entities have been created to govern and promote health information exchange and work with the federally-funded Regional Extension Centers authorized to help implement EHRs in physicians' offices. Often these are the same organization.

Patient Look-up Model of Health Information Exchange

The HIE is based on a communication network model that facilitates the movement of electronic data among nodes on the network. What is generally considered the health information exchange model can be referred to as the "patient-lookup" model. When a clinician enters a patient's identifying information into the HIE portal, it connects to a medical record repository and uses database software to search out all available electronic medical records from the data sources on the network (Just & Durkin, 2008). The records thus aggregated are then displayed on the computer screen for a physician to select. Because the records form a longitudinal record on the patient from disparate sources, a physician can obtain a broader view of the patient's medical history than might be available from paper records. Records can include demographics, discharge notes, continuity of care records, problem lists, medications, lab results, encounter histories and so on. The availability of records is dependent on the number and type of participants who join the HIE as data sources and on the data sharing rules embedded in HIE participation agreements (Kolkman, 2011; HIE Guide Work Group, 2009).

A representative use case of the patient-lookup model can be seen in the Emergency Department where a patient comes in without records. The ability to send a record request to the community HIE allows the Emergency Department physician to find vital information on the patient, potentially reduce duplicate tests and provide more informed care and treatment. This use case is pictured in Figure 1, in which an emergency room physician can draw on data resources in the hospital and from the community HIE.

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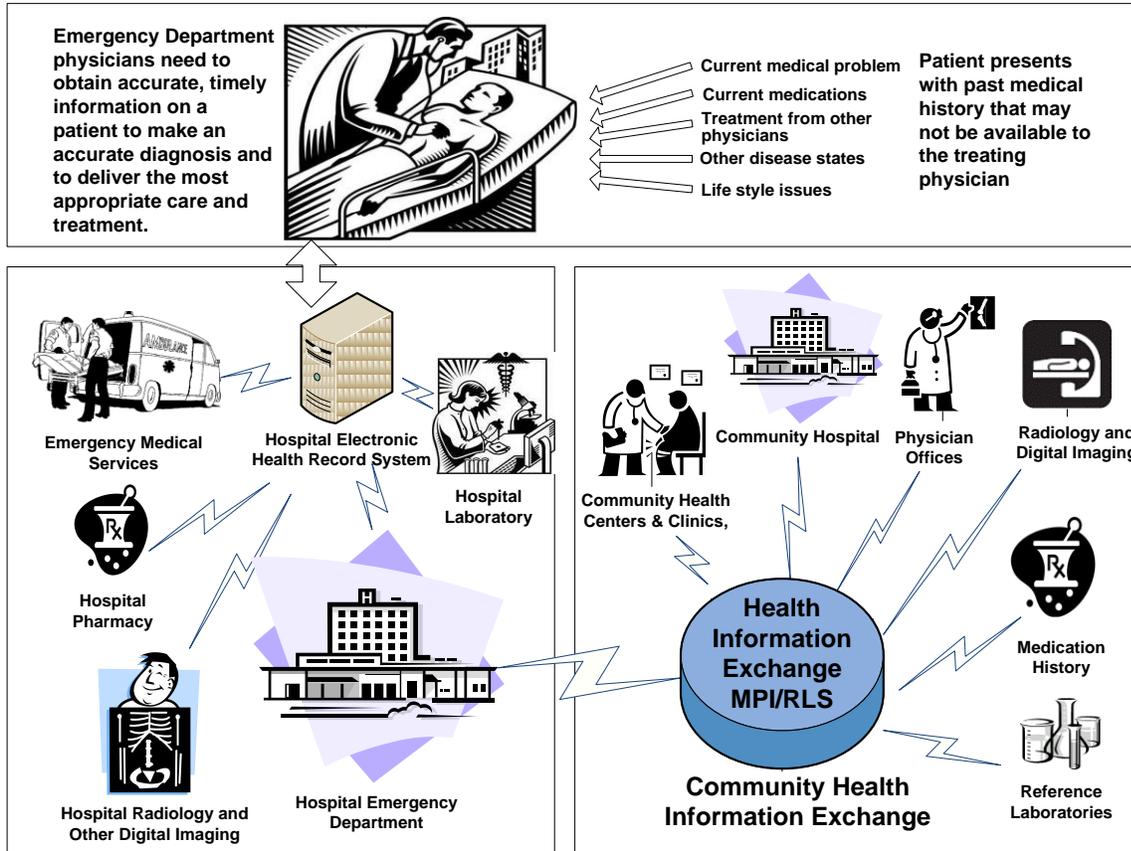


Figure 1. Emergency Department Health Information Exchange Use Case

The technical infrastructure of the HIE is more complicated than the simple description of the patient look-up model. There are both hardware and software requirements that allow a physician to submit a request for a patient's records, accurately identify that patient and match her or him to a correct set of medical records before delivering a listing of them within several seconds. A typical HIE query starts from an online portal that is an entry point for a query, or it can be embedded in the physician's EHR, which is connected to the HIE over an HL7 interface and across an encrypted, secure network connection, typically using the CONNECT standard (Health Level Seven, 2004; Office of the National Coordinator for Health IT, 2010). The cost of creating interfaces between HIEs and data sources has been a significant constraint on their rapid development.

Queries are generally submitted one at a time and the patient identifiers are matched to demographic information contained in a Master Patient Index (MPI), which is a registry for patient identification. Accurate patient identification is essential in a functioning Master Patient Index and a software standard such as the Patient Identity Cross Reference and Patient Discovery Query (PIX/PDQ) Manager is often employed to locate the correct patient (Dimitropoulos, 2009; IHE International, 2010). Once the patient is identified, the HIE then accesses the Record Locator Service (RLS) that holds a listing of patient records from disparate data sources. Again, a software standard such as the Cross-Enterprise Document Sharing (XDS) application from Integrating the Healthcare Enterprise (IHE) is used to locate and access records from any of the data sources participating in the HIE (Majurski, 2011; Ruggeri, et. al., 2011.)

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The records returned to the clinician also reflect numerous standards. A patient summary may be packaged in the Continuity of Care Document (CCD) (Healthcare IT Standards Panel, 2009) ; a digital x-ray or other image may need to be viewed with a Digital Imaging and Communications in Medicine (DICOM) viewer (Mustra, et. al., 2008; IHE International, Inc, 2011a; 2011b; 2011c). These and other similar technical standards are essential factors in the interoperability of electronic health record systems. Without technical standards such as these, each proprietary software system would require its own separate interface to connect to the network. One of the important duties of an HIE governance organization is to specify the technical standards under which all participants operate.

Another example of the need for standards applies to common nomenclature. For example, the naming conventions for laboratory results are typically unique to the lab, and are not consistent even between the largest reference laboratory companies, LabCorp and Quest, for the same lab test. For an EHR to receive a set of laboratory results and save them as structured data requires that they be translated into a standardized format. The benchmark developed to normalize the laboratory results is the Logical Indicators, Indicators, Numbers and Codes (LOINC) standard. LOINC bases its identification of lab results using six attributes: the component or analyte that is measured, the property observed, the timing of the measurement, the type of sample, the scale of measurement and the method of measurement. The use of these six identifiers allows a lab result to be fully described and distinguished from any other lab result. Without this step of standardization, laboratory results from different reference laboratories could not be compared for patient care management (McDonald, et al, 2010).

The use and deployment of these technical standards ultimately fall under the purview of the HIE governing organization that must ensure the interoperability of EHRs and the community HIE, and must be implemented by the HIE technical vendor. Equally complex for the HIE governing organization are the social, legal and political constraints developed to maintain the privacy and security of each patient's protected health information and to manage the rights and responsibilities of participants in the record exchange.

Secure Messaging for Health Information Exchange

A second approach to health information exchange is secure messaging, in which a physician can use an encrypted e-mail application to send medical records securely to another physician for treatment purposes. Most EHR systems offer secure messaging but often cannot exchange records with EHRs from a different vendor.

In 2010, the Office of the National Coordinator for Health IT (ONC) funded the development of a secure messaging platform, the Nationwide Health Information Network Direct Secure Messaging (NwHIN Direct) application (<http://wiki.directproject.org/>). The intent of ONC was to develop a policy framework and a set of standards that would enable a simple and scalable service over the Internet for the secure exchange of records between doctors (Office of the National Coordinator for Health IT, 2011c). NwHIN Direct is a secure, encrypted e-mail program that allows providers to send and receive e-mail messages and attachments containing a patient's clinical data. Its implementation is generally overseen by the State Designated Entity and state HIE governance entity. The secure e-mail service does not require providers to use an EHR or purchase special software. If a physician meets the registration requirements and has an Internet connection, he or she can use NwHIN Direct. Providers participating in the Medicare or Medicaid EHR Incentive Program can use NwHIN Direct as a means to qualify for Meaningful

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Use by exchanging electronic data that can be saved in an EHR (Office of the National Coordinator for Health IT, 2011a).

NwHIN Direct connects health care providers through Simple Mail Transfer Protocol (SMTP) but takes this one step further by employing the Secure/Multipurpose Internet Mail Extension (S/MIME) standard, using public key encryption for secure e-mail communication (Office of the National Coordinator for Health IT, 2011a). Because it is built on Internet-based e-mail standards, there is no need for a central network authority and NwHIN Direct is scalable to include anyone in a provider's professional network.

NwHIN Direct uses the X.509 digital certificate standard that identifies the user as a trusted participant in the exchange and allows him or her to securely transmit and receive protected health information. The certificate guarantees that users will abide by a set of rules which create a circle of trust (Housley, et. al., 1999; Giles, 2012). Users connect through a Health Information Service Provider (HISP) that maintains the certificate authority for each participant. The HISP also maintains a Provider Directory to allow providers to locate the NwHIN Direct address of any of any other physician participating in the e-mail network.

Both of these approaches are covered under the governance oversight of the state-level HIEs, but the patient-lookup model is generally the center of governance attention and drives decisions on data-sharing and patient authorization requirements. The secure messaging model is often equated with the direct physician-to-physician communication of a fax used for treatment purposes (Health IT Policy Committee, 2010a), while health information exchange is associated with the need for patient consent and enhanced security to maintain the privacy and confidentiality of patient records.

Values of Governance in Health Information Exchange

Following the passage of the American Recovery and Reinvestment Act in 2009, a nation-wide project was initiated to build an HIE infrastructure that would support the exchange or records for the coordination of care all across the United States. One of the key actions of ARRA for building this nationwide network was to require each state government to establish a "state-designated entity." These organizations would be responsible for managing the funding for state-level HIE provided in the Act and for engaging resources within the state to actually construct the HIE infrastructure. With this action, the federal government passed the role of HIE governance to the states. Following ARRA, ONC launched the HIE Cooperative Agreement program for state-level HIEs and governance of HIEs by the state-designated entities became an important state issue. Governance of local HIEs is manageable, since many of the health care stakeholders are familiar with each other; at the state level governance takes on greater complexity in part because the diversity of stakeholders can increase substantially, especially in large states, and the effort to foster collaboration and data-sharing increases exponentially.

The Value of HIE Governance in Convening Health Care Stakeholders

The eHealth Initiative, one of the premier associations voicing support for health information exchange efforts, publishes an online HIE Toolkit that provides organizational, legal, technical and business advice and resources for HIEs (<http://www.ehealthinitiative.org/hie-toolkit.html>). In its opening section on governance, the HIE Toolkit presents the basic value proposition that "Governance is the foundation of a health information exchange initiative (HIE). It is the first

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step, and the most important, in the process of forming and implementing an HIE” (eHealth Initiative, 2011a).

The type of governance structure that is established, the mission and value orientation of the governing entity, its legal status and even its funding strategies are determined by the participation of its stakeholders and their needs and resources. Thus, while governance in general is a key factor for HIE, the form and structure through which health care stakeholders are brought together for collaborative decision-making is critical, and creates the foundation for sustainability of operation. Community buy-in and participation are a major value that good governance brings to the successful exchange of health information among providers.

The State Level HIE Consensus Project, sponsored by the Foundation of Research and Education of the American Health Information Management Association (AHIMA), proposed that the governance role “consists of neutral convening and a range of explicit coordination activities that facilitate data sharing and HIE policies and practices among statewide participants (State Level Health Information Exchange Consensus Project, 2008). This simple sentence is fraught with implications about what it means to be neutral and which body has the authority to convene stakeholders, let alone undertake coordinating the level of activity that will result in policy creation and health information exchange.

The value of governance of HIE is seen by its embodying a number of traits that must be combined successfully. The governing body “is generally responsible for setting strategy, securing funding, and exercising oversight over the operational work of the HIO” (Alfreds, 2009, p.15). Again, it is reiterated that the state-level HIE must function as a neutral coordinating body, convening stakeholders and working with the potentially divergent interests of health care competitors to mitigate potential conflicts between them. (State Level HIE Consensus Project, 2009; Bakalar, 2008). According to the National Governor’s Association, the HIE governing body should be made up of a balance of health care stakeholder who work together to set strategy for the operational and business activities of the HIE (Alfreds, 2009). From these examples, it is evident that one of the key values that a governing body offers to an HIE is its ability to bring competing interests to the table to work out agreements for the exchange of health care information to enable the coordination of care among doctors and patients.

The Value of HIE Governance for Data Sharing

The development of an HIE directly impacts issues of data sharing and trust among health care providers. These are sensitive issues, covering control of the data, data stewardship, trustworthiness and accountability. A major value that the governing entity brings to stakeholders is as the neutral, trusted convening entity that can work with competing interests to build trust, ensure accountability and clarify agreements about how different health care stakeholders can exchange data.

The National Committee on Vital and Health Statistics (NCVHS) argued that maintaining accountability for proper data stewardship was an important value of governance of HIE (National Committee on Vital and Health Statistics, 2010). Health data stewardship refers to an organization’s ability to guarantee that personal health information is used appropriately. “The purpose of stewardship is to realize the greatest possible benefit from the effective and appropriate use of data while minimizing the risk of harm” (Kanaan, et. al., 2009, p.2). Responsible data stewardship strengthens trust that an organization will be held accountable for

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the proper use of an individual's health information.

The HIE governing organization thus plays a critical role in maintaining rules of stewardship while developing the data sharing agreements that contractually bind participants in the exchange of health information and set the foundation for health care stakeholders to work together. It is also responsible for holding participants accountable to the rules and to their roles in the data exchange. (State Level HIE Consensus Project, 2008). How the HIE governance organization is created, who is brought to the table and how it functions to create consensus around sharing clinical records is critical to the development of a state level HIE (Alfreds, 2008).

Another role of the governing entity in establishing data sharing agreements is to maintain a balance between the trust requirements of the health care community and its patients and the requirements of state and federal law. Data stewardship and the control of medical records are written into state and federal laws that specify the requirements of record storage, record protection and the limits of record sharing. Federal laws such as the Health Insurance Portability and Accountability Act (HIPAA), Family Educational Rights and Privacy Act (FERPA) and the Public Health Services Act contain strict guidelines for maintaining the security and privacy of records and provide for penalties in the case of a breach that releases records improperly. HIPAA limits the transfer and use of patient records for treatment, payment and operations only. HIPAA allows physicians to exchange medical records with another physician for treatment purposes but also allows patients the right to "opt-out" of sharing their records. While HIPAA was enacted to facilitate the exchange of medical records, health care providers sometimes misinterpret its intent and use it to limit access to their records.

Most states also have statutes that protect specific classes of records, such as mental health notes, HIV information and drug abuse treatment, requiring physicians to obtain patient authorization before transferring them to another physician. While both state and federal laws set constraints on the exchange of a patient's medical records, state laws prevail when they are more strict than HIPAA. Some state laws require the patient to actively "opt-in" by authorizing the transfer of records over a health information exchange, while other states endorse the "opt-out" approach.

These two issues of opt-in versus opt-out of record exchange form a major challenge for the governance of health information exchange and for setting exchange policies (Goldstein, et. al., 2010). To make things more complex, some states have addressed the issue through statute, others through administrative rules and others through the subscription agreements for joining the health information exchange. The lack of consistency of medical record laws from state to state is a challenge to governance of health information exchange and one factor in the variance of governance models across the states (Pritts, et. al., 2009).

Value of HIE Governance in Bridging Public and Private Sectors

The HIE governance organization, be it the State-Designated Entity or some other organization, plays a critical and valuable role in bridging the interests of the state with those of private sector health care providers. Each state in the HIE Cooperative Agreement program is taking its own approach to establishing the HIE governance model to oversee health information exchange. There are many similarities and many differences. In some states, the state level HIE governance organization was created by statute before ARRA and became the State-Designated Entity. In other states the State-Designated Entity was created by Executive Order, while in others by appointment of the Governor. In all cases, a primary role of the State-Designated Entity is to

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manage the HIE Cooperative Agreement with the ONC (Covich, et. al., 2011).

The locus of control for the HIE governance organization differs by state also. In some states, the HIE governance organization is controlled by the state government through a state agency that directly oversees the development of the state-level HIE or manages another technical or administrative organization that takes responsibility for the HIE. In other states the HIE governing organization is an independent, not-for-profit organization that takes on the responsibility of developing the state-level HIE for the State-Designated Entity. The form of governance structures thus adapts to the unique requirements of each state, though many states are moving from the state-driven direct governance to a not-for-profit governing body.

In each case, the HIE governance organization plays a unique and valuable role as the mediator between state interests and the private health care sector. It “serves as a neutral and skilled resource for convening diverse statewide stakeholders and leading and coordinating consensus-based efforts to develop and implement a statewide road map for interoperability” (Dierker, 2008). To succeed in this role, the HIE governing organization has to address and facilitate agreement on numerous issues surrounding the exchange of medical records both for public health and for private providers. It has to represent the interests of both the state government and private enterprise. Finally, the HIE governing organization has to become the vehicle by which competing public and private interests are coordinated and combined.

Determinants of Value for Governance of Health Information Exchange

The Markle Foundation, as part of its Connecting for Health series, argues that governance is dynamic, embodying a number of decision-making and policy-making stages, and that each stage may have different participants of institution engaged in the process. Markle proposes three main value components of governance for health information sharing: 1) clear goals and objectives; 2) processes for the development, coordination, oversight and enforcement of policies, standards and services; 3) a clear set of policies, standards and services. The HIE governing body must ensure participation, representation, accountability, transparency and effectiveness at each stage of HIE development to enable the secure and trusted exchange of health care information (Markle, 2012). The state-designated entities or the HIE governing organizations must be able to engage their communities of interest, coordinate policies and standards, engage in business development and hold participants accountable for their use of health data.

The characteristic values of the HIE governance organization can be summarized into the following characteristics:

Authority

The HIE governing body must be granted the authority to engage with stakeholders as a convening and coordinating body. Under the ONC HIE Cooperative Agreements, each state government nominated a State-Designated Entity, either a state agency or a not-for-profit Health Information Organization. With this designation, the authority to convene health care stakeholders was established as well as start-up funding from ONC. However, it is up to each state-designated entity to craft its governance model and determine the extent to which it put together public-private partnerships. Some state Legislators have crafted state law designating the state-level HIE, others have relied on Executive Orders or on the current HIE environment to delegate authority for state-level HIE. Every state is unique.

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Leadership

The state-level HIE governing body will be expected to take the lead in decisions that define expectations for the HIE, grant power to participants and verify their performance. It must take the lead in aligning HIE policies and practices with the legislative and regulatory environment, then develop consistent and cohesive policies to manage the processes and decision rights for participants in the state-level HIE.

Neutral Convener

The HIE governing organization must serve as a bridge between stakeholders at the local, regional, state and national level. The role of the convening is to create a trusted entity by facilitating professional and consumer input. It must make local Regional Health Information Organizations (RHIOs) or hospital Integrated Delivery Networks (IDNs) part of the state-level HIE, as well as bringing in consumer advocate groups part of the system to balance the health care rights and needs of all residents. The HIE governing organization must engage communities and build trust relationships at the local, regional and state level, realizing that regional and statewide governance is as important as local governance. It has to understand health care stakeholder needs at all levels and meet those needs through public policy. Health care stakeholders in the community must be brought to recognize and to buy in to what is being done by state-level HIE.

Coordinate Policy Development and Strategic Planning

The state-level HIE must deliver the processes and organizational capacity to support HIE serving all health care stakeholders. The statewide entity can drive public good by enabling the development of local as well as state-level HIEs. Its role is to develop policy and implementation guides to ensure that local, regional and state-level operators of HIEs act in coordinated fashion and it serves as a means for consensus on the adoption of HIE standards. Private and public actors must work together to achieve the goals of the HIE based on a realization that everyone is better off negotiating around differences and collaborating toward progress.

Business Operations

The HIE governance organization will have to address business models for the state-level HIE and to plan a strategy for sustainability. It will have to deal with technical operations and determine what it takes to build, operate and maintain the HIE, even if the HIE operations are undertaken by a technical vendor that is contracted to the HIE governing organization. In this situation, the HIE governing organization must distinguish between the coordination of effort and actual HIE operations. Nonetheless, it will have to estimate the costs and resources needed to maintain the HIE, determine financing approaches to support HIE functions and develop and payment policies. Without clear business leadership, the state-level HIE may not become sustainable.

Accountability

In order to maintain confidence in the state-level HIE, the HIE governing organization must hold network participants accountable for their actions, or inactions. There must be clear rules that lay out to acceptable and proper uses of individual health information and the responsibilities of data stewardship. If the HIE is to build trust in its operations, it must be vigilant in the potential for health information to be misused or for health records to be improperly accessed. The state-level

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HIE must maintain the highest technical, operational and physical security to maintain the confidentiality of the health care records it holds and exchanges. As such, to protect itself and the data it holds in trust, the HIE must create and enforce penalties against the potential for unauthorized access, misuse or disclosure of that data.

Transparency

In order to gain the trust of its participants and its stakeholders, the HIE governing organization has to operate under the principle of governance with transparency and openness. It needs to rely on the professional trust of its members and its customers in order to succeed in its governance activities. The HIE governing organization needs to develop policies that make its meetings and decisions open to the public, and should accept input from all interested parties.

Case Study: Development of HIE Governance through Federal Initiatives

With the determinants of value for HIE governance established, it is instructive to turn to the case study of emerging state-level governing organizations for HIE. Few of these HIE governance organizations existed at the state level prior to the American Recovery and Reinvestment Act of 2009, and the state-designated entities are only three years old at this point. Their having to work through the principals of HIE governance to launch state-level networks becomes an interesting case study in how well the values of governance underlie their efforts.

A starting point for health information exchange began with the establishment of the Community Health Information Networks (CHIN) in the early 1990s. Their goal was to facilitate the exchange of health data among all members of the health care system, including providers, payers, managed care companies, clinical laboratories, pharmacies and others. The CHINs were an exciting concept, but due to technical and financial constraints, most CHINs were not successful (Soper, 2001). However, the CHINs did set the stage for the resurgence in health information exchange ten years later.

In 2001, the National Committee on Vital and Health Statistics proposed the development of the National Health Information Infrastructure (NHII) to facilitate the exchange of medical records for the coordination of care. The study compared multiple health care settings and focused on an infrastructure that facilitated information sharing and “health-oriented interactions” more so than just technical data systems. (National Committee on Vital and Health Statistics, 2001). The study finished by recommending the creation of a permanent office in HHS to oversee the creation of the NHII.

In 2004, President George W. Bush announced the creation of the Office of the National Coordinator for Health Information Technology (ONC) and the Secretary of the Department of Health and Human Services (HHS) appointed Dr. David J. Brailer, MD, as the first National Coordinator. ONC was to become the major federal conduit for funding health information technology projects, but the first set of demonstration projects to promote health information exchange and engage with community HIE governance efforts came from the HHS Agency for Healthcare Research and Quality (AHRQ).

AHRQ Health Information Exchange Grants

In 2004 and 2005, AHRQ initiated a set of research grants to promote health information exchange under its Health Information Technology (Health IT) Portfolio (Agency for Healthcare

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Research and Quality, 2006). The intent of the grants was to support health information exchange projects that would use telecommunication and information technology to provide clinical information to physicians at the point of care. The demonstration projects were funded to develop and evaluate patient indexing systems, facilitate interoperability among health care providers for the coordination of care and explore strategies to create sustainable health information exchange. One goal of the projects was to generate data that would show improvements in the quality and effectiveness of care related to the exchange of medical records (Agency for Healthcare Research and Quality, 2004).

Between 2004 and 2005, AHRQ made awards to a number of institutions including universities, regional health information organizations and health information networks and state agencies in six states, as shown in Table 1.

Table 1. AHRQ State and Regional Demonstrations in Health Information Technology Awardees

State	Contracting Institution	Governing Organization	Description of Project
Colorado	University of Colorado Health Sciences Center	Colorado Regional Health Information Organization	Develop a state-wide HIE for physician access to clinical records.
Delaware	Delaware Health Information Network	Delaware Health Information Network	Develop a state-wide health information exchange for physician access to clinical records
Indiana	Indiana University School of Medicine	Indiana Network for Patient Care	Develop HIE and implement a State-wide public health surveillance network share emergency department data.
Rhode Island	State of Rhode Island, Department of Health	Rhode Island Quality Institute	Develop a Master Patient Index to facilitate interoperability and sharing patient data.
Tennessee	Vanderbilt University Medical Center	Mid-South e-Health Alliance	Implement a regional data sharing and interoperability services in three counties.
Utah	Utah Health Information Network	Utah Health Information Network	Expand current statewide network for the electronic exchange of patient administrative and clinical data.

The lessons learned from these projects indicated that the technical development of the health information exchange was actually the least challenging part of their operations. Of more import was the ability to manage the project and apply strategic business planning, and most importantly to enable strong governance to ensure health care stakeholder engagement in the project and

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maintain responsiveness to the needs of the community. Appropriate governance of projects with this scope is the most valuable means to ensure the success of clinical data sharing. The grant recipients all noted that the sense of engagement and ownership of the health information exchange process in a community fostered trust in the health information organization and establishing trust is essential to successfully implement HIE (Yi, et. al., 2011).

It was of great benefit for the recipients to identify business partners who would participate in the exchange of data and involve them in program decisions. This helped foster a sense of ownership in the HIE and to invest them in the success of the project. The recipient HIOs found that reaching out to patient advocacy groups and other health care stakeholders and allowing them to voice their concerns about privacy policies or the data to be exchanged helped create community trust and fostered participation. It is interesting to note that the HIOs funded by AHRQ are now among the leaders of HIE in the nation. (Yi, et. al., 2011).

ONC Nationwide Health Information Network Awards

NHIN Prototype Architecture Project, 2005-2007

In 2005, ONC announced a program to demonstrate the Nationwide Health Information Network (NHIN) architecture for the exchange of patient records. The demonstration projects were expected to validate the “network of network” concept of the NHIN by connecting communities and health care organizations without the need for a centralized infrastructure. The project was intended to demonstrate the HIE architectures that could be used to provide interoperability among health care participants, and make a show of functionality based on a set of use cases that included the exchange of laboratory results, electronic data from EHRs, interoperability with personal health record (PHR) software and biosurveillance. In addition, the recipients were to demonstrate how their system would maintain the confidentiality and security of all data.

Four major IT companies received awards for this project, each of whom engaged with a number of health care providers in different parts of the country. These companies included:

Table 2. NHIN 1 Prototype Architecture Awardees

States	Contracting Institution	Participating Organizations
West Virginia		West Virginia Medical Institute
Kentucky	Accenture	Eastern Kentucky Regional Health Community
Tennessee		CareSpark
		North Carolina Healthcare Information and Communications Alliance (NCHICA)
North Carolina	IBM	North Carolina Division of Public Health
New York		Taconic Health Information Network Community (THINC)
		New York State Dept. of Health
Indiana	CSC	Indiana Health Information Exchange
Massachusetts		MA-SHARE

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California		Mendocino HRE
Colorado		Quality Health Network
California	Northrup	Santa Cruz RHIO
Ohio	Grumman	University Hospitals Health System

The technical demonstration of interoperability was the focus of this project, so governance was of the responsibility of the health care facilities in each of the consortia. Each of the technical solutions demonstrated interoperability with EHRs and PHRs, showed that different technical architectures could support the same decentralized HIE solution and that the NwHIN could use standardized interfaces to support interoperability. The project did not offer any new knowledge on governance of HIE (Gartner, 2007).

NHIN Trial Implementations Project, 2007-2009

In 2007, ONC commissioned a second phase of the NHIN project, the “NHIN Trial Implementations,” that sought to engage a group of nine of health care organizations in a trial implementation of the NHIN “network of networks.” (Kuperman, et. al., 2010). The participants were required to demonstrate technical expertise in health information exchange by deploying specific use cases developed by ONC. They were also expected to actively engage their communities in a governance structure that had already developed trust relationships among health care stakeholders. A major requirement was for each participant to be an “ HIE that demonstrates an open and participatory governance process supporting state, regional or non-geographic health information exchange with involvement from a broad and representative range of health care-related organizations” (Office of the National Coordinator for Health IT, 2007, pp. 22-23).

The NHIN Trial Implementation project pushed the need for governance much more so that the prototype project. Participants were expected to ensure transparency in all meetings, ensure open selections for governing board members and provide for conflict of interest requirements for all members. Participants had to provide full descriptions of their governance processes and had to demonstrate the extent to which they achieved the trust and buy-in of their members.

The technical requirements for the implementations extended the use cases of the first prototype project and added core services that formed the basis of technical operations. The use cases formed a critical foundation for the exchange of records because they provided the context in which record exchange would take place. Each participant had to deploy at least one use case in its health information exchange project, as shown in Table 3.

Table 3. NHIN 2 Trial Implementation Awardees

States	Participating Organizations
Virginia	MedVirginia
Tennessee	CareSpark
Delaware	Delaware Health Information Network

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Indiana	Indiana University
California	Long Beach Network for Health
New Mexico	Lovelace Clinic Foundation, New Mexico Health Information Collaborative
New York	New York eHealth Collaborative
North Carolina	North Carolina Healthcare Information and Communications Alliance
West Virginia.	West Virginia Health Information Network

As a group, each of the participants continued to demonstrate ongoing leadership in health information exchange and in their governance of the data sharing. One of the important outcomes of the NHIN Trial Implementation was the creation of a workgroup among the trial participants who developed the first draft of the NHIN Data Use and Reciprocal Support Agreement (DURSA). “The DURSA is a legal agreement created to promote and establish trust among the Participants. It codifies a common set of trust expectations into an enforceable legal framework, and eliminates the need for point-to-point agreements” (DURSA Task Group, 2011, p i). The DURSA was created to be a comprehensive agreement that multiple participants could sign for the purpose of engaging in health information exchange using mutually agreed upon national standards for data sharing.

By using a set of common standards, the DURSA creates a framework of trust among its participants and establishes a level playing field of responsibilities, obligations and expectations for each participant. It also ensures that all parties to the agreement will follow the same set of rules and guidelines to protect the security of their respective health information networks and the privacy and confidentiality of the protected health information that is exchanged. The DURSA is a “living document” that has been updated several times since its first publication in 2009. As a document developed solely for the purpose of addressing the requirements of health information exchange, the DURSA creates the baseline for any state to use, or to take as a starting point to develop a similar data-sharing agreement among its HIE stakeholders (Gravely, 2011).

American Recovery and Reinvestment Act of 2009 – Leveraging State Level HIE Governance

In 2009, the United States Congress enacted the American Recovery and Reinvestment Act of 2009 (ARRA) as the centerpiece of its stimulus package. Embedded in ARRA was the Health Information Technology for Economic and Clinical Health Act, or HITECH, which contained fundamentally transformative language addressing the adoption and implementation of health information technology. The HITECH Act established ONC as a permanent Office in the Department of Health and Human Services (HHS), headed by the Coordinator for Health Information Technology. HITECH empowered ONC to carry out a broad set of strategies to facilitate the adoption of electronic health records systems and “to support regional or sub-national efforts toward health information exchange” (American Recovery and Reinvestment Act, 2009, p 65).

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Health Information Exchange Technical Infrastructure

In the HITECH Act, The Secretary of HHS was directed to invest in the technical infrastructure necessary to “support the nationwide electronic exchange and use of health information in a secure, private, and accurate manner, including connecting health information exchanges.” ONC was expected to promote the development of an infrastructure that would support telemedicine, interoperability among clinical data repositories and public health reporting (American Recovery and Reinvestment Act, 2009. pp 132-133).

The actual construction of the state-level HIE infrastructure was made the responsibility of state governments, through a state-designated entity (American Recovery and Reinvestment Act, 2009). This mandate placed the responsibility of governing the HIE on the state itself, whether through a state agency or through a not-for-profit organization. These requirements set the stage for the creation of new HIE governance bodies in each state and territory.

The HITECH Act specified a number of programs to promote and promote, build , implement and support health information technologies in all forms, tightened privacy and security measures under HIPAA and required HIE organizations to sign Business Associate Agreements to enhance the security of health information being exchanged. The HITECH Act was not a specific about governance of these programs, but stipulated that the “National Coordinator shall establish a governance mechanism for the nationwide health information network.” (American Recovery and Reinvestment Act, 2009. p 119).

Governance of the Nationwide Health Information Network

The HITECH Act established two new committees under ONC to provide quasi-governance activities of the Nationwide Health Information Network, though their function is to provide recommendations rather than oversight to ONC. The HIT Policy Committee was created to develop a policy framework for the development of the health IT infrastructure, and develop standards and specifications for building the infrastructure for secure health information exchange. The mission of the HIT Policy Committee also included developing policy standards for the security of health information exchange, public health biosurveillance and telehealth monitoring technologies. The HIT Policy Committee was expected to offer a balanced representation to all sectors of the health care system and serve as a forum for stakeholder input, which is its major governance function.

The second committee created was the HIT Standards Committee. Its job was to recommend technical standards and specifications for health IT and specifically for the exchange of health care records to overcome the major technical barriers to interoperability among health IT systems. The HIT Standards Committee was expected to represent all health care sectors, including providers, health plans technology vendors, researchers and experts in privacy and security and to serve as a forum for health IT stakeholders to provide input to ONC on the development of technical standards for HIEs. The HITECH Act outlined the need for governance through inclusivity and stakeholder buy-in from each committee, but provided no powers to either committee to actually govern the development of HIE at the national level. This was left to ONC as a federal agency (American Recovery and Reinvestment Act, 2009).

In 2010 the HIT Policy Committee formed a Governance Workgroup to consider the requirements of governance for the newly renamed Nationwide Health Information Network (NwHIN). The Governance Workgroup issued a draft recommendation on its governance roles

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and responsibilities at the end of the year. The workgroup recommended nine principles of governance for the NwHIN (Health IT Policy Committee, 2010b):

1. Transparency and openness: Governance approach should maximize openness and engage the public and data-sharing participants.
2. Inclusive participation and adequate representation: Demonstrate preference for including diverse stakeholders and encourage robust participation.
3. Effectiveness and efficiency: Functionality of HIE governance should have a goal of maximizing efficiency and effectiveness.
4. Accountability: Stakeholders must be held accountable and responsible to the national agenda, which should be reflected in governance mechanisms.
5. Federated governance and devolution: Governance structure should allow multiple entities to take ownership of decisions closest to them and with the greatest stake in resolution. The federal government should take the lead in areas essential to maintaining public trust in its meeting NwHIN goals.
6. Clarity of mission and consistency of actions: The rights, responsibilities and obligations of all stakeholders should be clearly documented and decision-making should be consistent.
7. Fairness and due process: Governance processes should include due process and responsiveness to stakeholders and governance decisions should be fair for participants.
8. Promote and support innovation: Governance should create conditions for innovation and should minimize administrative burdens so as not to inhibit innovation.
9. Evaluation, learning and continuous improvement: Evaluation of governance should be appropriate and fair based on clear performance guidelines.

These recommendations were developed following an open comment period in which the Governance Workgroup solicited comments on a number of topics. The comment topics included governance experiences from people who had implemented HIEs, especially how they established authority and executed the governance process. Comments on experiences with governance models in other domains was also solicited, with comparisons of public-private relationships and the appropriate control of data sharing. The issue of establishing trust through governance was of major interest, and comments were requested how to establish trust among multiple stakeholders, how the privacy and security of patient data was established and how effective participation was established. The two last areas of interest were accountability and interoperability and comments were sought based on the experiences of existing HIEs (Lumpkin, 2010). The results of this feedback, and the recommendations proposed by the Governance Workgroup were implemented in an RFI that ONC published in May, 2012, soliciting guidance on how to establish a “voluntary framework for entities that facilitate electronic exchange” for purposes of validating them as a trusted entity (Federal Register, 2012. P. 285550).

Federal Health Information Technology Strategic Plan

The HITECH Act directed ONC to update the Federal Health IT Strategic Plan that it had published a year earlier, in 2008. ONC was required to address specific objectives and metrics

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with respect to implementing HIE, such as strategies for incorporating privacy and security protections for HIE, educating the public about health IT and developing strategies to ensure quality health outcomes from the use of health IT for the coordination of care. ONC was also to establish a framework to coordinate the recommendations and policies that stemmed from the HIT Policy and Standards Committees (American Recovery and Reinvestment Act, 2009).

The Federal Health IT Strategic Plan, published in 2008, addressed the governance of HIEs as an integral part of its strategy by inserting a governance objective in each of its strategic goals. At that time, the ONC strategic plan argued that “planning, consensus building, priority-setting, and consistent approaches to implementing policies can best be achieved through appropriate structures and mechanisms for collaborative governance” (Office of the National Coordinator for Health IT, 2008. p 4). In the view of the 2008 ONC strategic plan, proper governance of HIE should include individuals and organizations who are health care stakeholders cutting across both public and private sectors.

In 2011 ONC published its second Strategic Plan, as required by the HITECH Act. In this new plan there is little discussion of HIE governance, except by way of reference. ONC states that it will “establish a governance mechanism through rulemaking that seeks to include accountability and oversight of nationwide information exchange” (Office of the National Coordinator for Health IT, 2011b. p 18). The governance mechanism proposed by ONC was published as a Request for Information in 2012 and was based, in part, on the recommendations of the Governance Workgroup of the HIT Policy Committee (HIT Policy Committee, 2010b). The approach taken by ONC in the RFI proposed the “creation of a voluntary program under which entities that facilitate electronic health information exchange could be validated with respect to their conformance to certain ONC-established “conditions for trusted exchange (CTEs)”” (Federal Register, 2012. P. 28544). Under these governance guidelines, the ONC was offering a validation or credentialing mechanism for HIEs to promote trust rather than an approach that promotes engaged stakeholder collaboration and input. This approach was a step back from the consensus-building priority of governance in its previous strategic plan in 2008, and the evidently “hands on” approach of the HIT Policy Committee recommendations. In September 2012, the ONC pulled back from the governance plan established in the RFI in favor of leading through action and guidance rather than direct regulation (Office of the National Coordinator for Health IT, 2012).

Policy Drivers for Health Care Transformation Using Health Information Technology

The HITECH Act represented a fundamental change in the way political drivers were pushing electronic health record systems and health information exchange into the health care arena. Multiple federal agencies were engaged in promoting, funding and influencing a shift in the way health care records were recorded, stored, obtained and exchanged. The technical infrastructure received a considerable amount of incentive funds to moving it in the direction of a national health care infrastructure for health information exchange. But the change was mostly technically-oriented. There was little guidance for how the complex and expensive HIE systems would be overseen and governed in their development.

Subsequently, ONC included governance expectations in its HIE Cooperative Agreements awards, but left the actual governance of the state-level HIEs open to the states. It was up to the states and territories to determine what governance mechanism would work best for them and what approach would provide the appropriate balance of leadership and consensus to create and

maintain the technical infrastructure. This is where the value of governance lies, in its ongoing collaborative efforts to manage the important issues of health record exchange and among treating physicians and the consent of patients for that exchange.

Development of State Level Health Information Exchange Governance Models

The development of community and state-level HIEs between 2004 and 2011 had occurred at an accelerating pace across the period and provided models of HIE governance for the state-designated entities created under ARRA. In addition to the state agencies, universities and Health Information Organizations spurred by the AHRQ and ONC funding programs, other organizations were also emerging as viable HIE entities. Not all were successful, and many struggled to find a sustainable business model. The one thing in common to all of the nascent HIEs was the concerted attempt to develop a governance model that worked to create buy-in, develop collaborative partnerships among health care competitors and facilitate the acceptance of data sharing among health care providers.

In 2004, eHealth Initiative circulated its first HIE survey to evaluate the health information exchange environment across the country. These surveys have continued every year since. (eHealth Initiative, 2005; 2006; 2007; 2008; 2009; 2010; 2011). eHealth Initiative created an evaluation framework of six stages that identified at which stage an HIE had reached in their survey. The first four stages were increasingly functional, but only in Stage Five was the HIE fully operational, transmitting data and sustainable. In the final stage, the HIE had moved beyond its initial sphere of operations to include a broader set of stakeholders (eHealth Initiative, 2005). The data from the eHealth Initiative surveys on the number of fully operational HIEs in Stages Five and Six is shown in Figure 2. Each of these HIEs had to demonstrate success in their governance models for bringing community stakeholders to the table and for developing the rules of data sharing among them. These governance models would become the basis for furthering the exchange of health information under the new requirements of the HITECH Act.

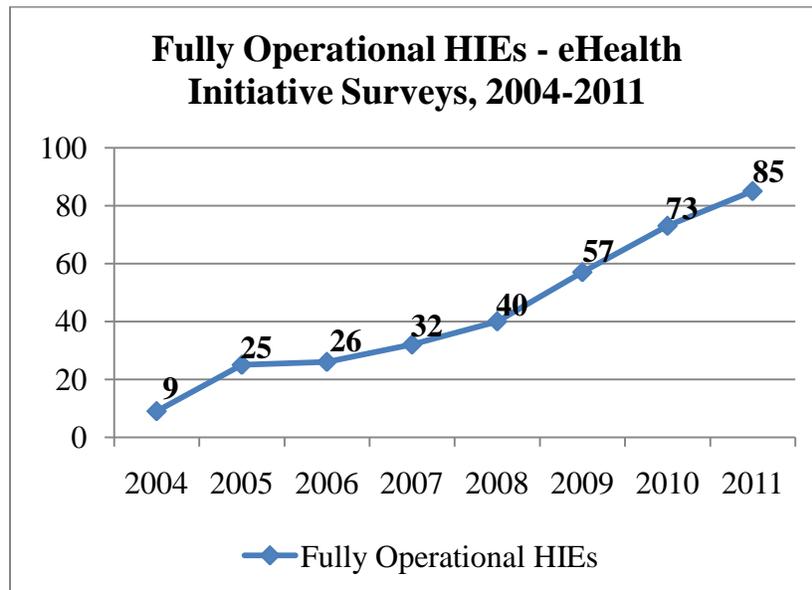


Figure 2. eHealth Initiative Survey of Fully Operational HIEs, 2004-2011

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Development of Governance among State-Level Health Information Exchanges

Following the passage of ARRA and the HITECH Act in 2009 and the opportunity for obtaining funds for the development of health information exchange infrastructure, states and territories were faced with the task of creating governance structures for their state-level HIEs. In states with existing RHIOs or Health Information Networks, the fundamentals of governance were present in the state. For other states, planning for HIE governance began with the launch of the ONC State Health Information Exchange Cooperative Agreement Program in 2009, which was intended to kick-start the planning and construction of HIE infrastructure in each state and territory.

The purpose of the HIE Cooperative Agreement Program was to “facilitate and expand the secure, electronic movement and use of health information among organizations according to nationally recognized standards” (Office of the National Coordinator for Health IT, 2009. p 7). Awards were to be made to the state-designated entities as specified in the HITECH Act. These could be a state agency, a not-for-profit or another organization as determined by the state’s Governor. The program’s intent was to develop a state-level HIE infrastructure based on statewide policies, governance and business operations models.

With the publication of the Funding Opportunity Announcement states started on the path of planning and building state-level HIEs. The program proposal required each State-Designated Entity to specify its plan for implementing state-level HIE along five dimensions: 1) Governance, 2) Finance, 3) Technical Infrastructure, 4) Business and Technical Operations, and 5) Legal/Policy (Office of the National Coordinator for Health IT, 2009). Each of these dimensions represented one major variable in the total strategy to develop state-level HIE. ONC left it up to each state to determine the HIE governance and technical model that it would follow; carrying out the plan would be accomplished through a negotiated, cooperative relationship between the state and ONC.

Under the State HIE Cooperative Agreement Program, the State-Designated Entity was responsible for creating a governance model for the state-level HIE. Governance was defined by ONC in terms of convening health stakeholders from both public and private sectors, creating trust relationships among them and achieving consensus for the best way to create the state-level HIE, as listed below (Office of the National Coordinator for Health IT, 2009).

- Base the governance approach based stakeholder buy-in, trust and collaboration.
- Establish goals and objectives for the HIE, based on the consensus of health care stakeholders and develop performance measures to track progress.
- Coordinate HIE efforts with Medicaid and public health.
- Develop a plan to ensure oversight of the HIE and to enforce accountability among participants.
- Maintain the flexibility required to adapt to future HIE governance requirements from ONC.

The actual governance model adopted by each state was determined by the authority vested in the State-Designated Entity by the Governor, or by the Legislature in states with statutory mandates. The governance model reflected the types of public-private policy approaches

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adopted by the state and the strategy for implementing the technical HIE architecture. Given the flexibility open to state-designated entities for designing state-level governance models, each state still faced four basic tasks for establishing that governance: 1) creating trust and stakeholder buy-in; 2) coordinating HIE strategic planning; 3) figuring out resources and sustainability; and 4) establishing accountability requirements (State-Level HIE Consensus Project, 2009).

To address the requirement to establish state-level governance bodies, each of the states took an approach that was unique to its needs, though there are many similarities. In many states, the locus of control for state-level HIE governance was an important issue, whether to establish it in a state agency or in an independent not-for-profit. For example, in 2005 the state of Vermont had authorized a not-for-profit, Vermont Information Technology Leaders (VITL), to develop and lead the state-level HIE. Following ARRA, the Vermont Legislature changed the governance control to the Office of Vermont Health Access, leaving VITL to manage the technical side of the state-level HIE (Vermont Agency of Human Services, 2010). This approach of locating control of the HIE in the government and managing it through a not-for-profit is common in many states. However, there is also a pattern emerging to transfer control and governance out of the state government into a not-for-profit.

The approach taken to construct the state-level HIE infrastructure differs depending on the designation of the lead HIE organization in each state and on the model chosen by the state government to manage and govern the development of HIE. The governance model, sometimes guided by state statute, determines who brings stakeholders to the table and how trust is built around their activities. Because the state-designated entities are authorized by the state government, each is dedicated to serving the policy interests of the government by serving the interests of stakeholders across the state to achieve the public good and to ensure the privacy and confidentiality of health information.

Because the State-Designated Entity is positioned between the state government and the private health care sector, it requires a neutral, reliable leadership that can develop the trust of all stakeholders. According to a survey of state-level HIEs, “even in states where government currently plays a key sponsorship role for early HIE efforts, it is most valuable for a state-level HIE entity to be a structure that engages, but sits outside of, state government” (State Level HIE Consensus Project, 2008). In this model, then, the role of the independent not-for-profit organization as the HIE governing entity brings value to governance by virtue of its independence and ability to represent all stakeholders.

HIE policy research identified several models of HIE governance that had emerged prior to the ONC HIE Cooperative Agreement program, but were very influential in creating the governance models that have emerged among the state-designated entities (Alfreds, 2009; Deloitte, 2006). The basic models for government-based HIE include:

- A government-led model, in which the state government runs the HIE directly and maintains immediate oversight of its use and governance.
- A public utility model, in which the government maintains a strong oversight and regulatory role, but the HIE is provided through a contract with a technical HIE vendor.
- A private sector led model, in which the state government plays only an advisory and stakeholder role in governance. The HIE entities are generally not-for-profit organizations that maintain a governance relationship with the state.

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- A private collaborative HIE model, often formed as a physician/payor collaboration, or as a private Independent Data Network among health care facilities or provider groups.

Each of these organizational and governance models display a different locus of control, different approaches to convening stakeholders, establishing trust for public-private HIE collaboration and most importantly, financing of the HIE operations. The government-led and public utility models reflect their source of government authority through the control they establish over the governing boards for HIE policy, for HIE operations and for oversight of the HIE. The private models reflect both government advisement and completely independent governance approaches. Under the HIE Cooperative Agreement Program, state-designated entities would follow on the first three models, but would have to work with and include any HIEs working under the fourth model. For the governance to work in any of these models, the State-Designated Entity has to reflect each participating organization's interests and must provide incentives for stakeholders to join the HIE, regardless of the locus of control. This is its important role as the neutral convener. It must also provide a mechanism for conflict resolution among competing interests because often, there are disagreements over who should sit on the governing boards of the developing HIEs, and this can hinder the formation of a functional governance model (West & Friedman, 2012).

A second approach for portraying approaches to state-level HIE comes from a report on emerging state HIE models published by ONC. In the report, they classify state approaches to HIE in four ways: 1) the Elevator; 2) the Capacity Builder; 3) the Orchestrator and 4) the Public Utility (Office of the National Coordinator for Health IT, 2010). Each of these models categorizes the levels of direct involvement that the State-Designated Entity takes in governance and development of the state-level HIE, but ONC focuses mainly on the technical aspects of the HIE rollout. For example the Elevator model focuses on establishing interoperability among health care providers, while at the other end of the spectrum the Public Utility model offers centralized HIE services across the state. The issues of governance are not discussed in detail in the report but are included in the summary table of the report. Nonetheless, it seems obvious that the requirements of HIE governance will change depending on the level of state control and technical implementation that is followed.

Another approach to categorizing governance models taken by an eHealth Initiative and Thomson Reuters research team outlined the issues raised by the variation in state HIE infrastructure approaches and offered a taxonomy of different state-level HIE models: 1) a centralized model; 2) a decentralized model and 3) a hybrid model. In their white paper, the authors argue that the governance functions for each model contains both advantages and disadvantages for statewide HIE development (Covich, et. al., 2011).

Centralized Model

The State-Designated Entity establishes the state-level HIE either directly or through a public-private partnership with a not-for-profit to provide core HIE services from a central technical platform for the entire state. Independent RHIOs, hospital-based IDNs, public health entities and other exchanges can connect to the centralized HIE. The governance advantages of this model are that governance oversight is for a single technical solution that can manage access, accountability and sustainability from a centralized position. The downside is that there are greater liability issues for the state and the need to maintain consensus across a diverse set of healthcare communities.

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Decentralized Model

The State-Designated Entity acts as a facilitator for the HIE, convening meetings of stakeholders, building trust as a neutral body and developing HIE policy for the public good. In this model, the State-Designated Entity does not provide core HIE services but coordinates local HIE infrastructure. Nonetheless, it has the responsibility to ensure that the state-level HIE is operational. The benefit of this model is that it leverages the community basis of existing HIEs, but both governance and technical challenges increase. The governance organization has to maintain trust and buy in from multiple stakeholder organizations, and must craft consistent public policy from potentially divergent perspectives.

Hybrid Model

The State-Designated Entity facilitates the development of statewide HIE and also provides HIE services as one of several HIE entities. The State-Designated Entity is still responsible for the construction of the state-level HIE, so must remain positively engaged in governance activities. The governance advantages of this HIE model are that it can still leverage existing community HIEs, and minimize its liability issues, while still driving unified public policy for the HIE. The governance challenge is again technical in that it must oversee the interoperability of multiple HIEs and manage input from diverse communities across the state.

Variations of Value from Governance of State-Level HIE

In each of the state-level HIEs discussed, there is evidence of state legislatures and state-designated entities working to engage in meaningful governance activities to carry out the requirements of the HITECH Act and the HIE Cooperative Agreement Program. In some states, the governance functions are working well; in others they are slowly being organized. When the various technical approaches to implementing the state-level HIE are multiplied by the different challenges of HIE governance models, the complexity and difficulty of deriving one best practice for governing data sharing and becomes evident.

The variants of organizational authority and control, the methods of convening diverse stakeholders and working toward consensus and trust, and developing public policies for participation, accountability and responsibility in the HIE network, all demonstrate that appropriate governance must be thought through carefully. In addition to these common governance values, the type of HIE infrastructure that is implemented, the technical requirements that differ between centralized and decentralized models and the level of technical coordination determined by the choice of HIE infrastructure all place pressure on the requirements of appropriate governance. The unique determinants of each State-Designated Entity mirror the needs of its unique communities, and the ability to draw stakeholders together and encourage competitors to compete on everything else except sharing the data is a challenge that must be addressed straight on to ensure the successful implementation of a state-level HIE.

Conclusions

The institution of governance oversight is critical for establishing successful health information exchange among a diverse set of health care providers. There are many concerns and issues about data sharing that create barriers to the effective exchange of health information. It takes a strong, neutral group of concerned people to bring the different health care stakeholders to the

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table to work through their differences to create some common ground for sharing the health care records for which they are data stewards. This role as the Neutral Convener is a key value for governance of the HIE because it must establish the trust among all participants and must display a preference only for maintaining an equal playing field for all. A related value for the governance body in its neutral convening role is Transparency of actions, in which all meetings, discussions and decisions are accomplished in the open. This value is essential to the formation of trust and for maintaining its credibility in the health care community.

There are other values that the HIE governance brings to the table. The HIE Governing body must have Authority vested in it, either by the community of health care stakeholders or, as in the case of the state-designated entities, by the state government. This is essential for its credibility and representation of all participants. With that responsibility comes the task of Leadership in articulating a vision of health information exchange that enables the sharing of health care data while addressing the concerns and issues of all stakeholders. One of the major requirements of the HIE governance body in its leadership role is Policy Development by which it negotiates consensus on the rules and expectations of implementing data sharing through an HIE. It then must express stakeholder agreements as a set of clear guidelines and policies that all participants are willing to follow and hold them accountable to the rules that are established. The governance value of Accountability is essential for maintaining the credibility and trust of HIE operations.

Finally, the HIE governing organization has to address the operational and business side of the HIE. For this responsibility it must apply the value of Strategic Planning to look to the future and determine how to bring in more participants in data sharing activities, engage their needs and work to develop policies and rules that benefit all participants. In addition to planning for the expansion of its membership, the governing body must apply skill in determining the appropriate Business Operations that will move it forward technically. It has to ensure that the HIE infrastructure maximizes its potential and the needs of participants and can maintain a sustainable revenue stream. These last two value function of the governance organization speak to its ability to build a business entity that can continue to operate and provide its members with a reliable technical infrastructure for the ongoing exchange of health information.

With the passing of ARRA and creation of state-level state-designated entities, the knowledge and lessons learned from developing local HIEs did not necessarily translate to the State-Designated Entity. The first issue to be dealt with was the locus of power and authority for the State-Designated Entity, whether within the state or with a state-level not-for-profit. Some states had already worked through this decision, like Rhode Island and Delaware, in part due to prior work on HIEs with AHRQ and ONC funding. Most states had to work through this problem for the first time, which was a challenge. Also, whereas local HIE governance could deal principally with a known set of health care stakeholders, the State-Designated Entity had to bring stakeholders together from disparate parts of the health care system, such as physicians, hospitals, payers, health departments and consumers. Some stakeholders do not have the same goals or objectives in endorsing health information exchange, so these minor conflicts add to the difficulties of the governing body in negotiating consensus and achieving a coordination of effort among participants (eHealth Initiative, 2012a).

There are other problems facing the state-designated entities. They have the common problems of day-to-day governing Board participation, but also have to deal with issues such as a lack of

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technical knowledge of HIE among Board members as well as competing interests, if not conflicts of interests, among Board members (eHealth Initiative. 2012a). In addition, government control of the state-level HIE does not necessarily engender trust in participants, although it can. However, the pattern in many states is to migrate the control of the state-level HIE from a government agency to an independent not-for-profit. This could indicate the difficulty of establishing a functioning HIE with state resources, or it could indicate a general perspective on the appropriate locus of control. The approach that state governments and the state-designated Entity have taken to building out the HIE infrastructure, whether a centralized or decentralized or hybrid model, raises governance issues unique to that model. It is still too soon to determine which is most successful.

Yet, the requirements of good HIE governance do not go away, and the state-designated entities are the generally responsible organizations, many mandated by state statute, to get the job done. The success of the federal initiative to create a national HIE infrastructure will be determined by the steady efforts of the state-designated entities as they engage in the HIE governance of their state-level HIEs and apply the lessons learned from their community-based counterparts.

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