

# THE EVOLUTION OF THE STATE HEALTH INFORMATION EXCHANGE COOPERATIVE AGREEMENT PROGRAM: STATE PLANS TO ENABLE ROBUST HIE

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ENABLE ROBUST HIE

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## Overview

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The purpose of the State HIE Cooperative Agreement Program, authorized by section 3013 of the Public Health Services Act (PHSA) and as amended by the Health Information Technology for Economic and Clinical Health Act (HITECH Act) passed as part of the American Reinvestment and Recovery Act (ARRA), is to “facilitate and expand the secure, electronic movement and use of health information among organizations according to nationally recognized standards.”<sup>i</sup> The Funding Opportunity Announcement (FOA) defines health information exchange (HIE) as the process of sharing health information electronically between organizations in accordance with nationally recognized standards.<sup>ii</sup>

The program is based on the premise that timely sharing of health information can improve health care quality, efficiency, and safety, can enable more effective public health programs and clinical research, can give providers more comprehensive clinical information for use in treating patients, and will ultimately positively impact the health of all Americans.<sup>iii,iv</sup>

The Office of the National Coordinator for Health IT (ONC) contracted with NORC at the University of Chicago to conduct a multi-year evaluation to understand the effect and implications of the program. The current issue brief places the current program in historical context and represents an important starting point for assessing the status of the program one year after its initiation. In preparing this document, we used information gathered from existing literature, program documentation and conversations with key program stakeholders to trace the history of federal initiatives to promote HIE in the United States, focusing on how the State HIE Cooperative Agreement Program has evolved since it became part of federal law and offering insight on how the program may influence the HIE landscape in the future. The insights described at the end of this brief can be explored in greater depth and rigor in subsequent phases of the evaluation.

## The History of HIE Efforts in the United States

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Efforts to establish HIE have been underway in the United States for over twenty years. The Community Health Management Information Systems (CHMIS) program was formed by the Hartford Foundation<sup>v</sup> in 1990 to foster the creation of a centralized data repository in seven geographically defined communities. Many participating communities, however, struggled with securing cost-effective technology, interoperable data sources, stakeholder trust, and strong political support.<sup>vi</sup> Similar initiatives—known as Community Health Information Networks (CHINs)—began in the mid-1990s with the intention of sharing data between providers in a more cost-effective manner, but many met significant challenges and the majority was not sustained.<sup>vii</sup>

Following the 1999 Institute of Medicine Report, “*To Err is Human*,” which identified medical errors as a significant threat to the health of Americans that could be addressed,<sup>viii</sup> a new generation of federal efforts emerged to address these concerns, in part through the effective use of information technology. These, largely bipartisan, initiatives included the 2004 creation of the ONC within the U.S. Department of Health and Human Services (HHS) under the administration of President George W. Bush.<sup>ix</sup> Also in 2004, the Agency for Healthcare Quality and Research (AHRQ) Health Information Technology Portfolio funded \$166 million in grants and contracts to improve healthcare decision making, support patient-centered care and to improve quality and safety.<sup>x</sup> This funding included the State and Regional Demonstration (SRD) project to support

state and regional level HIE.<sup>xi</sup> AHRQ awarded \$5 million grants to six states: Indiana, Delaware, Rhode Island, Tennessee, Colorado, and Utah. The SRDs established information exchange over large geographic areas and generated best practices for developing policy, governance, trust and technical solutions to meet the needs of broad stakeholder groups.<sup>xiii</sup>

The Medicare Modernization Act (MMA) of 2003 authorized AHRQ and the Centers for Medicare and Medicaid Services (CMS) to award \$6 million grants to five states to test initial standards in electronic prescribing (eRx) to assess how efficiently and effectively prescriptions for Medicare Part D beneficiaries could be transmitted electronically. Findings from these pilots identified workflow and technical considerations that informed the final rule establishing standards for eRx under MMA.<sup>xiii</sup>

In addition to these federally funded initiatives, HIE developed organically in several markets and academic settings. The most well-known examples are HealthBridge in Cincinnati and the Indiana Health Information Exchange (IHIE). Another important, but often overlooked, setting for information exchange besides exchange between affiliated providers, is within closed systems such as large integrated delivery networks.

### Changing Definitions for HIE

The general understanding of HIE has changed over time. When the ONC was created in 2004 the terms “Health Information Exchange,” and “Regional Health Information Organization” (RHIO) were used interchangeably for several years. In 2008, the National Association for Health Information Technology (NAHIT) published definitions for five key health IT terms, including standardized and distinct definitions for “HIE” and “RHIO,” whereby “HIE” was designated as the *process* of exchanging health information and RHIO a regional organization exchange information. It has become clear since then that even where a central infrastructure exists to facilitate health information exchange it is not always regionally focused, paving the way for the adoption of the more general term “health information organization,” or “HIO.”

### The Role of HITECH in Promoting HIE

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Although development of electronic health records (EHRs) and HIE have been ongoing for over 20 years, recent progress in this arena has intensified due to passage of the ARRA and HITECH in February 2009, which created unprecedented new funding and incentives for the adoption of both tools.

While the goal of enabling health information exchange at the state and territory level is central to the State HIE Cooperative Agreement Program, HIE is also an important component of other HITECH initiatives such as the Beacon Community Program, the Health Information Technology Extension Program, and the Strategic Health IT Research Projects (SHARP) Program. HIE is also central to the Medicare and Medicaid EHR Incentive Program and to meaningful use guidelines, which describe the ways in which EHR technologies must be implemented and utilized for a provider to qualify for incentive payments.<sup>xiv</sup> Several Stage 1 meaningful use objectives involve health information exchange including electronic prescribing, exchange of clinical care summaries, integrating laboratory results into EHRs and reporting of immunizations and syndromic surveillance data to public health departments.<sup>xv, xvi</sup> HIE has the potential to enhance coordination among providers and to improve the quality and efficiency of

health care, and is therefore a critical component in improving the overall performance of the U.S. healthcare system.

## The State HIE Cooperative Agreement Program

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On August 20<sup>th</sup>, 2009, ONC issued the original FOA for the State HIE Cooperative Agreement Program, announcing that the agency would distribute \$564 million to states and territories to enable HIE within their jurisdiction. Participating states would enter into a partnership with ONC, collaborating with the agency on the planning and implementation of their individual state HIE programs. This emphasis on collaboration distinguishes the cooperative agreement program from a grant program, in which the funding agency would have more limited involvement in state-level activities.<sup>xvii</sup> By March 2010, 50 states and 6 territories (hereafter “states”<sup>1</sup>) received initial awards to begin planning for and establishing their programs.

The cooperative agreement FOA, issued before Stage 1 meaningful use regulations were finalized, was intended to assist states in developing a framework to facilitate health information exchange. Activities were to focus on “developing statewide policy, governance, technical infrastructure and business practices needed to support the delivery of HIE services,” according to the FOA. As part of this program, states were expected to accomplish the following:

- Develop state-level directories and enable technical services for HIE within and across states;
- Remove barriers and create enablers for HIE;
- Convene healthcare stakeholders to ensure trust of and support for a statewide approach to HIE;
- Ensure that an effective model for HIE governance and accountability is in place;
- Coordinate an integrated approach with Medicaid and public health; and
- Develop or update privacy and security requirements for HIE within and across state borders.

The original FOA emphasized that states were allowed flexibility in choosing a model and were expected to take an incremental approach to developing their infrastructure. While the FOA did not explicitly support or preclude an HIO model of exchange at local, regional, or state levels, in context of the HIE environment at the time, some of the FOA language was interpreted to favor an HIO/hub and spoke model<sup>2</sup> of exchange. For example, the FOA states that program funds may be used to “develop or facilitate the creation of a statewide architecture.” In addition, the FOA mentions HIOs as an avenue for advancing exchange; that resources may be used to advance the development of essential tools such as a Master Patient Index (MPI); and that program funds should leverage existing efforts. As a result, several states were inclined to pursue a single or plural HIO approach, especially those with significant HIO activity prior to the program.

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<sup>1</sup> Within the Funding Opportunity Announcement, the term “state” was defined to include the District of Columbia and the U.S. territories – Puerto Rico, U.S. Virgin Islands, Guam, the Northern Mariana Islands, and American Samoa for purposes of the State HIE program agreement.

<sup>2</sup> Wherein a centrally managed hub facilitates the exchange of information among individual entities (or “spokes”).

The Program Information Notice (PIN)-001, issued July 28, 2010, emphasized the program's support for all forms of HIE, particularly more market-based approaches.<sup>xviii</sup> The PIN further clarified several program requirements, notably engagement with key stakeholders, enabling trust, building sustainability, ensuring consistency with national standards, and monitoring and tracking meaningful use requirements as they pertain to HIE. It also advised states that "the immediate priority of the State HIE Program is to ensure that all eligible providers within every state have at least one option available to them to meet the HIE requirements of meaningful use in 2011."<sup>xix</sup> These clarifications communicated the ONC's desire to encourage exchange through a broader set of market-based approaches in unambiguous terms. Its guidance to states regarding meaningful use was also a response to concerns that providers would fail to meet meaningful use because of a lack of HIE options.

This evolution, combined with the series of serious assessments that occur when programs evolve from existing largely in documents such as FOAs, proposals and consortium agreements to actual implementation, has, in some cases, led many awardees to pursue different directions than they had originally proposed or anticipated. This progression occurred as a natural consequence of both the scale and magnitude of the efforts, as states move to establish governance and operational principles, promote cultural change on the part of consortia of Agencies and organizations involved in the program and encourage behavioral change on the part of individual stakeholders such as providers that would take part in HIE.

## Evolution of Program Focus/Objectives

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Information gathered from state applications, in the six months before the PIN and final meaningful use regulations were published in July 2010, suggested that many states were considering establishing technical infrastructures that would either take advantage of existing HIOs present in the state efforts or develop statewide HIOs in areas where the level of HIE prior to HITECH had been very limited. The PIN provided prescriptive guidance, including how states should establish a multi-stakeholder process, monitor and track meaningful use, develop key deliverables, provide leadership for the program, and establish a strategy for standards-based exchange activities. The PIN also identified for states areas where action was mandatory as well as those in which the guidance provided for discretion.

The path states followed after the PIN was issued was shaped by a number of overarching components:

- The PIN acknowledges that since ONC funding was a one-time investment, it would be challenging "for states to implement and operate comprehensive statewide health information exchange services" with only the available funds. As such, ONC encourages states to carefully consider how to use available HITECH funds to fill gaps, leverage existing information exchange activities, and assure coordination with key stakeholders (Medicaid, public health, providers, consumers) and trading partners to promote secure and sustainable standards-based HIE. ONC emphasized the need for states to focus on enabling HIE thus the PIN encouraged states to consider all forms of exchange capabilities, using the approach most appropriate to their environmental context to enable eligible providers to meet meaningful use requirements. The PIN also clarified that states could play a role in facilitating services through leadership, governance, stakeholder

engagement, and policy levers. It also acknowledged that states were not required to “directly provide or construct technology infrastructure or services.”

- The PIN notes that exchange options available to providers in every state should be “trusted, secure and transparent information sharing...addressing elements of the HHS Privacy and Security Framework.” This requirement stipulates how states shall use a wide range of approaches including governance, policies and procedures, laws and regulations, and other mechanisms to create a transparent process.
- ONC emphasizes that states should focus on how to sustain information sharing between different stakeholders, given the vast literature on the challenges of creating sustainable HIE.<sup>xx</sup> ONC will likely issue further guidance on this topic. It is clear that states are expected to consider approaches that take into account their local markets and leverage existing tools and resources to create an environment that will sustain HIE, and furthermore that sustainability should not be focused around organizational entities alone.

States were required to submit and receive approval for their Strategic and Operational Plans that described their overall approach to enabling HIE as required by the FOA.<sup>xxi</sup> However, only five states had obtained approval prior to the issuance of the PIN.<sup>xxii</sup> The PIN guidance motivated states to significantly reevaluate and, in many instances, amend their approach to be incremental and in some cases market-driven. The emphasis shifted from establishing technology infrastructure to enabling HIE in a manner which takes into account the current status and organization of HIE. Many states have since submitted revised Strategic and Operational Plans to ONC to address the various requirements of the PIN. States had to ensure their plans included the following components:

- an environmental scan and gap analysis;
- approach to governance;
- approach to eRx, laboratory results reporting and clinical summary exchange;
- approach to technical infrastructure;
- strategies to address providers without an available option to exchange information;
- coordination with HITECH programs;
- coordination with Medicaid and public health; and
- an approach to privacy and security.

Since the PIN was issued, all 56 states and territories have worked closely with ONC and received approval for their plans.<sup>xxiii</sup> Although this phase of reassessing, and in many cases revising, the state plans has implications for implementation timelines, in the long run states are likely to benefit from having plans that are context-appropriate and more feasible to execute.

## The Direct Project

The Direct Project was initiated in early 2010 to support simple point-to-point forms of exchange between trusted entities.<sup>xxiv</sup> It is a set of standards, policies and services that offers a secure solution for providers to achieve Stage 1 meaningful use and to enable inter- and intrastate exchange using a ‘push model.’<sup>xxv, xxvi</sup> Direct, as an enabler of secure data transport, is designed to support a variety of fundamental care delivery use cases including the exchange of clinical care summaries, laboratory test results, public health reporting data, and Admission



Discharge and Transfer (ADT) data. Though HIO/RHIO efforts attempted to move the healthcare system to a level beyond point-to-point exchange, there are many clinical use cases for which information will likely continue to be exchanged this way. While Direct supports a ‘push model’ for the secure exchange of information between trusted entities, a few states, for example, Rhode Island and Maine have adopted technical approaches that overcome the potential limitation of Direct not supporting robust, query-based exchange; these states use Direct for provider-provider exchange and to route clinical summary records to a centralized repository. Whether states implement Direct will be determined by their overall HIE approach and the current HIE market. As of April 2011, the Direct Project had eight pilot sites with a variety of goals, from improving the process for exchanging referrals to enabling the distribution of reports between acute care facilities and community-based providers. These pilot sites, New York, Tennessee, California, Rhode Island, Connecticut, Texas, Minnesota and Missouri, have demonstrated various use cases and have provide an initial “proof of concept” on the use of Direct.

### Challenge Program

ONC announced a second funding opportunity in December 2010 to “address persistent barriers to nationwide health information exchange and interoperability.”<sup>xxvii</sup> This program, State Grants to Promote Health Information Technology (Health Information Exchange Challenge), distributed more than \$16 million among ten current cooperative agreement grantees. Awards were granted to encourage development and innovation in the following five specific categories: 1) Achieving health goals through HIE; 2) Improving long-term and post-acute care transitions; 3) Consumer-mediated information exchange; 4) Enabling enhanced query for patient care; and 5) Fostering distributed population-level analytics. Because the grants were awarded recently, the effects of the program on HIE nationwide and on state programs have yet to be assessed but are highly anticipated. In particular, the innovations and technical solutions developed through the Challenge Grant program are expected to be used and adapted by states and HIOs nationwide.

### Implications and Early Findings

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In the first six months of 2011, the NORC evaluation team conducted ninety minute discussions with HIT/HIE leaders from 27 states. In addition, NORC began a systematic review of all of the approved Strategic and Operational Plans. While these evaluation activities are still underway and findings from a more robust set of analyses are forthcoming, we provide some initial insights based on this work as it relates to the topic of this brief below. Although ONC clarified their expectations of states, states continue to have significant flexibility in how HIE is enabled and made available to providers which is evident in the different approaches taken in approved state Strategic and Operational Plans. Each plan takes a unique approach to addressing the required five domains based on the particular environment within which the state operates. NORC’s initial evaluation activities also suggest there are some common themes emerging.

### States are Pursuing Different Organizational Models

In most cases, the state was the direct recipient of the ONC funds. In approximately twenty percent of cases, the money was given directly to State Designated Entities (SDEs) that met the

requirements under Section 3013 of the PHSA.<sup>xxviii</sup> These requirements instructed that the entity must “... be a not-for-profit with broad stakeholder representation on the board; demonstrate that one of its principal goals is to use health IT ... through authorized and secure electronic exchange of health information; and adopt ... fair and nondiscriminatory participation by stakeholders.”<sup>xxix</sup> In some cases, even where the state was the direct recipient of the funds, the state opted to maintain contractual and legal responsibility with ONC and identified an SDE-like entity to implement the approved plan. Approximately 50 percent of states initiated the program using an SDE or an SDE-like model. Findings from NORC’s initial discussions with state leaders indicate that there are advantages when direct funding recipient is the state, especially from the perspective of rule-making authority and control. However, this arrangement has its disadvantages; in particular, formal, state-level processes around issues like procurement can restrict the state’s ability to execute the program swiftly and efficiently. Moreover, our discussants indicated that states may lack flexibility to adjust their approaches once a particular course has been planned and approved. As the evaluation progresses, NORC will continue to monitor these emerging themes and use them to assess the impact of organizational models on effective and efficient HIE implementation.

### States are Pursuing Different Technical Models

Based on a review of half of the plans submitted by states, ONC derived four high-level categories to describe the states’ strategic technical approaches<sup>xxx</sup>:

- **Elevator.** Rapid facilitation of directed exchange capabilities to support Stage 1 meaningful use with intention of moving to additional phases of exchange over time.
- **Capacity-builder.** Bolstering of sub-state exchanges through financial and technical support tied to performance goals.
- **Orchestrator.** Thin-layer, state-level network to connect existing sub-state exchanges.
- **Public-utility.** Statewide HIE activities providing a wide spectrum of HIE services directly to end-users and to sub-state exchanges where they exist.

Initial discussions conducted by NORC with state HIT/HIE leaders suggest that each state’s technical approach is unique in the constellations of services it provides. For example, the orchestrator model describes an overarching “thin-layer state-level network” that includes messaging and directories, but states pursuing this model often choose to provide a range of additional services. These additional services may include a central repository, data transformation such as mapping proprietary laboratory codes to Logical Observation Identifiers, Names and Codes (LOINC), an MPI, and/or a record locator service (RLS). Notably, the approved state plans indicate that approximately half of states provide services associated with more than one of the models listed above. Nevertheless, this categorization scheme provides a common language to compare and contrast state initiatives and their progress, as well as a framework for ONC to support state efforts with appropriate technical assistance and oversight. Based on preliminary review of a subset of plans and initial discussions, we offer the following observations related to state models:

- **State Models are Evolving over Time.** The variety in HIE models indicates that, in addition to very carefully structuring their approach to be consistent with the requirements of the PIN, states are building their models upon existing information

exchange activity and capacity. At the same time, states are establishing and pursuing short- and long-term goals that will require the evolution of states' models. In the short-term, the focus is on compliance with Stage 1 meaningful use requirements. For example, states classified as "elevators" are typically those with small populations and/or a few local HIEs and/or who are in the early stages of building a statewide exchange fall within the elevator model (e.g., Alabama, Alaska, Georgia and Hawaii). According to HIE/HIT leadership, these states are relying on the elevator model as a "stop gap" strategy for meeting meaningful use requirements. In the long-term, the goal of states is to build a robust, sustainable statewide approach to support comprehensive exchange by adopting the approach of an orchestrator or a public utility model.

- **States Report that Direct Can Play an Important Role.** Many states are in the process of exploring the different ways Direct can be used to meet their immediate, short-term need: offering providers at least one option to meet Stage 1 meaningful use requirements. While Direct pilot projects are paving the way to enable a "push" model for different use cases, it is unclear whether there is sufficient demand in various markets to justify a large scale implementation of Direct services. In NORC's discussions, state leaders expressed the concern that once providers have the option of Direct, they may be reluctant to switch to more robust forms of HIE. In NORC's evaluation, it will be important to see for what specific "use cases" Direct appears to be best suited and how it evolves over time.
- **State Models are Leveraging Existing Information Exchange Activities.** NORC's review of approved plans shows states are leveraging existing HIE infrastructures. Where there are mature nodes of information exchange, states are connecting the nodes or promoting expansion through grants and incentives. Indiana, for example, plans to use program funding to incentivize local HIOs, providers, critical access hospitals and trading partners (i.e., laboratories), to enable information exchange and will not establish state-level technical infrastructure. Additionally, states may be pursuing a dual approach of bolstering the local HIOs and establishing a minimum state-wide infrastructure with a select number of central services. For example, CalConnect in California provided funding to expand local HIO efforts and at the same time is establishing a "thin-layer" of state level services.

### States are Pursuing Different Implementation Approaches

Some states have opted to develop statewide models, while others choose to connect local or regional nodes, or to offer Direct services. States pursuing statewide HIO approaches are in some cases leveraging a predominant RHIO in the state, as is the case with the Colorado Regional Health Information Organization (CORHIO), or they are expanding on an established statewide HIO, as with the Delaware Health Information Network (DHIN) and in Rhode Island, CurrentCare. Some states are choosing to leverage local HIOs and offer state-level services to fill gaps. For example, Washington, is starting out with a central hub and data transformation services to edit or transform information, and is partnering with sub-state networks to ensure coverage of the entire state. With regard to Direct, an initial review of the state plans and discussions with state leaders suggest that states are leveraging existing HIE infrastructures.

States' approaches to Direct include certifying health information service providers (HISPs)<sup>3</sup>, establishing minimum service and interoperability requirements for HISPs, contracting with HISP vendors in the states, and developing technical services and serving as the HISP themselves.<sup>xxxii</sup> In the latter case, some states are pursuing this as a short-term strategy and plan to contract for the services in the long-term. It will be necessary to carefully monitor the tremendous diversity in how states implement their models to determine which approaches are likely to foster swift and/or advanced information exchange capability.

### Implications of Decoupling the Governance and Technical Role

Prior to the State HIE Cooperative Agreement program, many state-wide HIE initiatives were led by a single entity that controlled both policy and technology. Under the current program, in many states, separate entities are likely to play governance and/or technical operator roles and the roles of these entities are likely to evolve over time. This decoupling of policy and technology is far from universal (e.g., in South Carolina and South Dakota the state is responsible for both the governance and technical architecture of a state-wide HIE), many states pursuing a decentralized approach are doing so through different avenues. In particular, early interviews suggest varying roles for the state itself. In one approach, the state or an SDE establishes policies and acts as a neutral convener for the entities involved, while the technical operations are being performed by the local HIOs/RHIOs. For example, Indiana established an SDE to serve in the governance role for state HIE activities but technical operations will be conducted by local HIOs. Examples of success decoupling technical and governance functions can be found at the regional and local level as well. For example, the Hudson Valley HIE uses the Taconic Health Information Network Community as the governing organization and MedAllies as the technical service provider; however, this approach is still relatively new at the state level. There are other instances in which the state and an SDE share the governance function. Maryland is one such example in which the Maryland Healthcare Commission receives the state funds but shares its governance authority with the SDE, the Chesapeake Regional Information System for our Patients (CRISP). Given the relative infancy of the state HIE program, states have yet to encounter significant challenges associated with these governance models, nor have they been able to assess the models' long-term utility. States' ability to enable HIE without, in many cases, having direct control of the organizations responsible for delivering on this charge, may create a novel set of challenges.

### Evolving HIE Vendor Marketplace

The move to enable HIE using a market-driven approach is creating a number of shifts in the vendor marketplace. These include EHR, Personal Health Record (PHR) and HIO vendors expanding their HIE services and new vendors entering the HIE market. Large EHR vendors are now offering a range of HIE solutions to expand their market share among ambulatory care

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<sup>3</sup> A Health Information Service Provider, or HISP, is a logical concept that encompasses certain services that are required for Direct Project exchange, such as the management of trust between senders and receivers. It may be a separate business or technical entity from the sender or receiver, depending on the deployment option chosen by the implementation. Retrieved from: <http://directproject.org/faq.php?key=faq>

providers and hospitals. The Direct Project has motivated some vendors to update their software applications to support the Direct specifications, and has led other vendors, like SureScripts and Quest MedPlus, to expand their exchange capabilities. Direct has also spurred vendors who are not traditionally involved in HIE, such as Verizon, to enter the market. Another consequence of market expansion is consolidation and acquisition. In the last year, two major health plans acquired HIE vendors: Medicity was acquired by Aetna and Axolotl was acquired by Ingenix, a subsidiary of United Health Group. While there are numerous theories on why health plans are now entering the HIE vendor space, the role they will ultimately play will be revealed in the coming months. Finally, there appears to be a growing market in franchising HIE services. Currently, Cincinnati-based HealthBridge is offering HIO services to different geographic areas, both within and outside state boundaries. These developments speak to a complex and rapidly evolving marketplace that is likely to affect all vendors and organizations offering HIE services in ongoing and unforeseen ways.

### Enabling Trust

One priority for states is ensuring the development of a privacy and security framework that adequately addresses the key principles highlighted in the HHS Privacy and Security framework: Correction; Openness and Transparency; Individual Choice; Collection, Use, and Disclosure Limitation; Safeguards; Data Quality; and Integrity and Accountability.<sup>xxxii</sup>

- ***States Are Making Good Progress Reviewing Privacy and Security Laws.*** Most states that NORC spoke with reported having completed their review of federal and state privacy laws. In addition, some of the states reported progress on changing or implementing the privacy laws necessary to enable HIE. Twenty of the twenty-seven states interviewed reported participating in the Health Information, Security and Privacy Collaborative (HISPC). Of this group, all indicated that HISPC provided a valuable foundation from which to build, and as a result, they had a good grasp of issues that create impediments to information exchange. The impact of privacy laws for HIV/AIDS, mental health, and substance abuse on HIE continues to be problematic for states to address. The experiences of the HISPC project suggest a collaboration model for state coordination/cooperation is beneficial in these areas.
- ***Privacy and Security Laws Will Continue to Evolve.*** Several states acknowledge that they have carefully reviewed the conformance of state laws with federal laws and have identified and rectified state laws creating barriers to HIE. As states begin to focus on interstate information exchange, they recognize that existing laws may need to be revised to align policies state-to-state.

### Approach to Sustainability Still Evolving

NORC's review of more than half of the approved plans and initial discussions with state HIE leaders indicate that states' plans for sustaining their HIE efforts are in the early stages of development. It is still unclear what innovative strategies will emerge to sustain information sharing over the long term, and after the conclusion of federal funding, in particular. Discussions with state HIE/HIT leadership reveal that in some states, the creation of central repositories is perceived as a fundamental building block for sustainability. These states believe that the collection, analysis, and reporting of this data would prove valuable to providers and other

stakeholders, particularly in the context of accountable care and bundled payments, and thus would be one approach to ensuring sustainability. Although many HIE stakeholders recognize the importance of having a viable long term strategy, there are no definitive answers at this point. Previous large-scale information exchange efforts suggest that sustainability may be slow to achieve and largely dependent on uptake by a critical mass before the true benefits of information exchange can be realized.

## Conclusion

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The magnitude of resources provided under the HITECH Act are unprecedented in the history of HIE and have succeeded in initiating widespread exchange activity. At this stage in the cooperative agreement program, states are enabling HIE through incremental approaches that build on existing information exchange activity and take into account prevailing market forces. Future evaluation activities should assess the relationship between specific models and state progress in realizing their program goals. Experiences gained from this program will provide valuable insights into varying approaches to HIE, as well as specific factors related to successful implementation and sustainability. This national initiative is a critical step towards the goal of advancing the electronic movement and use of health information based on national standards.

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