Evaluation of the State Health Information Exchange Cooperative Agreement Program: Early Findings from a Review of Twenty-Seven States

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EVALUATION OF THE STATE HEALTH INFORMATION EXCHANGE COOPERATIVE AGREEMENT PROGRAM: EARLY FINDINGS FROM A REVIEW OF TWENTY-SEVEN STATES

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The State Health Information Exchange (HIE) Cooperative Agreement Program, passed as part of the American Reinvestment and Recovery Act (ARRA), "facilitates and expands the secure, electronic movement and use of health information among organizations according to nationally recognized standards."[i] The strategy taken by the Office of the National Coordinator for Health Information Technology (ONC) is to support the development of exchange capabilities in an incremental fashion and fill gaps in the market to enable a wide variety of providers to exchange key health information. The ONC has funded NORC at the University of Chicago to conduct a multi-year evaluation of this program. This brief seeks to characterize the various approaches that states and State Designated Entities (SDEs) are taking to enable HIE, one of the key aims of the evaluation. We highlight early findings from a mixed method study of 27 states conducted approximately one year and six months since the inception of the State HIE Program. This brief will inform ONC, other policy-makers and HIE stakeholders about emerging approaches for enabling HIE; the rationale for the various approaches that states are pursuing; the progress of state implementation; and common challenges and barriers being faced by states.

Data Sources

NORC considered the following factors in selecting the 27 states included in this review: geographic diversity, variability in grantees' strategic approaches to enabling statewide HIE, the approval date of the states' strategic and operational plans (as an indicator of states' varying level of readiness to implement their plan), the presence of a Direct pilot[1] in the state, and the extent to which their approaches and activities reflect national trends (Table 1). NORC conducted discussions with 70 state health IT/HIE leaders in these states between January and July of 2011. Discussants taking part in these meetings included the Health IT (HIT) Coordinator (23) and/or SDE Directors (11), and other staff (27) HIE program managers, project managers and financial managers). NORC also reviewed and used content analysis to abstract core information from approved Strategic and Operational Plans for the 27 participating states. We also included responses from states that completed the 2011 eHealth Initiative survey of HIT Coordinators and SDE Directors (eHI Grantee Survey). The survey was conducted in June and July of 2011.

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[1] The Direct Project had eight local 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.

TABLE 1: Characteristics of Selected States in Comparison to National Trends

Variable	Category	Total States for Discussions (n=27)	%	All States and Territories (n=56)	% Nationally
Strategic Approach*	Elevators[1]	0	0%	1	2%
	Capacity Builders[2]	1	4%	1	2%
	Orchestrators[3]	5	19%	8	14%
	Public Utility[4]	4	15%	13	23%
	Elevator/Public Utility	3	11%	10	18%
	Elevator/Orchestrator	10	37%	18	32%
	Orchestrator/Public Utility	2	7%	2	4%
	Capacity Builders/Orchestrator	2	7%	3	5%
Direct Pilot	Yes	5	19%	8	14%
Plan Approval Date	Jan-Sept 2010	5	19%	8	14%
	Oct-Dec 2010	10	37%	15	27%
	Jan-March 2011	10	37%	22	39%
	April-June 2011	2	7%	11	20%
State Population	<2M	7	26%	19	34%
	2-5.99M	8	30%	20	36%
	6-10M	6	22%	10	18%
	>10M	6	22%	7	13%
% Rural counties	<6% or N/A	9	33%	18	32%
	≥6 and <11%	3	11%	5	9%
	≥11 and <21%	5	19%	13	23%
	≥21%	10	37%	20	36%

* High level strategic approaches developed by ONC.ii The table includes pure approaches (elevator, capacity-builder, orchestrator, public utility and hybrid approaches (elevator/public utility, elevator/orchestrator, orchestrator/public utility, and capacity builders/orchestrator). [1] Described as "rapid facilitation of directed exchange capabilities to support Stage 1 meaningful use. [2] Described as "bolstering of sub-state exchanges through financial and technical support, tied to performance goals. [3] Described as "thin-layer state-level network to connect existing sub-state exchanges." [4] Described as "statewide HIE activities providing a wide spectrum of HIE services directly to end-users and to sub-state exchanges where they exist."

Emerging Themes

In the sections below, we present findings from the State HIE Program evaluation in the areas of approaches to enabling statewide HIE (governance and leadership), stakeholder engagement, technical models and services, privacy and security, sustainability, and implementation.

Section I. Leadership Approaches to Enabling Statewide HIE

States have adopted one of three primary approaches to enabling statewide HIE: (1) A state-led approach (10 of the 27 states); (2) a SDE[2] approach (8 of the 27 states); and (3) a "SDE-like" approach (9 of the 27 states). **Factors that influence states' selection of approach include: level of HIE activity at baseline (i.e., HIE activity in the state when the Program began); availability of an existing organization that meets governance requirements addressed in the FOA; technical model preferred by state leadership and stakeholders; and the political environment at the time that the governance model was selected.**

STATE-LED APPROACH
- State is the direct recipient of ONC funds

SDE APPROACH
- Funds are given directly to the SDE, a non-profit organization designated by the state as eligible to receive Cooperative Agreement funding from the federal government

SDE-LIKE APPROACH
- An entity, like an SDE, shares HIE governance responsibility with the state, but unlike an SDE does not receive Cooperative Agreement grant funding directly from the federal government

NORC categorized the 27 states as having significant exchange, some exchange or minimal/no exchange based on content analysis of responses from state HIT/HIE leadership discussions and/or information abstracted from approved Strategic and Operational Plans. For example, when state leadership used terms like, "we are just starting out," and did not indicate knowledge of substantial pre-existing HIE in the state, they were designated as having "minimal or none" at baseline. NORC designated states that were able to point to operational HIOs in portions of their state as having "some" HIE, and NORC designated states that expressed confidence that they had high-level exchange as "significant." While this categorization is highly qualitative, it is noteworthy that four of the six states categorized as having "significant" HIE were recipients of State and Regional Demonstration Project funds through the Agency for Healthcare Research and Quality[iii] and continued the model initiated under those programs, an SDE-based approach, to further expand HIE in the state through the State HIE Cooperative Agreement Program. True SDE approaches predominate in states engaged in significant information exchange activity prior to the inception of the HIE Program (baseline); SDE-like approaches appear to be favored by states with some activity at baseline, and state-led approaches, in most cases, seem to be favored by states with limited exchange activity at baseline (Table 2). These data, although based on a small sample, strongly suggest that a state's history with HIE influences their approach to enabling HIE statewide ($p < 0.005$).

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[2] According to Section 3013 of the Public Health Service Act (PHSA), as amended by American Recovery and Reinvestment Act (ARRA), a state designated entity (SDE) is a non-profit organization designated by the state as eligible to directly receive Cooperative Agreement funding from the federal government.

Table 2: Leadership Approaches and Level of HIE in the State (n=27)

		Leadership Approach		
		SDE	**SDE-Like**	**State Lead**
Perceived Level of Baseline HIE Activity	Significant	6	1	0
	Some	1	7	4
	Minimal or none	1	1	6
The chi-square test result of 19.86 (p<0.005, df=4) indicates that a statistically significant relationship exists between the states baseline activities and their leadership models. *Given some cells have values less than 5; Chi-square may not be a valid test. **Source:** State HIE Leadership Discussions and Approved Strategic and Operational Plans*				

States unanimously report that they chose an appropriate leadership approach for their state, but indicate that there are advantages and disadvantages to each (Table 3). In general, states that selected a state-led approach report that it enhances their ability to provide direction and oversight, and to ensure transparency of program activities. All states, regardless of their approach, also report that state-led HIE efforts facilitate better interactions with State Medicaid and State Public Health officers often due to physical proximity or pre-existing relationships. However, five of the nine states with a state-led approach report that in the future they will re-evaluate their approach and consider designating a public-private entity to lead HIE efforts.

> The true SDE approach "brings the public and private sector together, with a joint accountability to make [the State HIE] succeed."
>
> --HIT Coordinator discussing the merits of a true SDE

In states with "true" SDEs, HIT/HIE leadership note the following advantages: the nimbleness and flexibility of the SDE versus the state government, and insulation from funding cuts as states try to balance their budgets. States with SDEs believe that they are also attractive to potential staff and stakeholders. In addition, the state and the SDE benefit from the fact that the SDE is not solely reliant on Cooperative Agreement funding to provide for overhead costs. Being in the private sector, SDEs can secure funding from other projects or, in three cases, from their role as the Regional Extension Center (REC). However, states taking this approach also report that coordinating with other state entities, such as Medicaid, can be more difficult since the SDE is located outside of the government. In these cases, the SDE relies on the HIT Coordinator to initiate and facilitate these relationships, which can significantly slow down coordination due to the extra steps and parties involved in the process.

SDE-like approaches try to maintain the flexibility of a SDE entity relative to procurement and hiring while maintaining transparency and connectivity to other state agencies through close association with the state. Directors of several SDE-like entities believe that working closely with the state, who as the grant recipient has a direct relationship with the federal government and ONC, allows them to devote more time to enable statewide HIE than if they had a direct funding relationship with the federal government. Another advantage reported by states using the SDE-like approach is the partnerships it promotes with private stakeholders.

Table 3: Advantages and Disadvantages of Approaches to Statewide HIE

Leadership Approach	Advantages	Disadvantages
State-Led	▪ Authoritative voice for program direction, oversight, and long-term stability ▪ Obligatory public accountability and transparency ▪ Competency in managing federal grants ▪ Access to other coordinating state agencies	▪ State procurement requirements ▪ Administration and directional changes ▪ Budgetary challenges ▪ Lack of responsiveness in adjusting to a changing environment
SDE	▪ Responsiveness to a changing environment ▪ Procurement and hiring flexibility ▪ Multi-stakeholder engagement and more diverse funding support ▪ Focused organizational and staff objectives ▪ Private sector management of health care data	▪ Role confusion of the HIT Coordinator and the SDE Director ▪ Less competency in managing federal grants ▪ Less access to state agencies and state decision-makers
SDE-like	▪ Same advantages as SDE Model ▪ Transparency and connectivity to state agencies through its close association with the state	▪ Role confusion of the HIT Coordinator and the SDE Director

Source: State HIE Leadership Discussions

In keeping with ONC's vision and guidance for the role of State HIT Coordinators, the majority of HIT Coordinators have responsibilities beyond those associated with the State HIE program.[iv] In only four of the 27 states is the HIT Coordinator solely responsible for activities related to the State HIE Cooperative Agreement program. In the remaining 23 states, the HIT Coordinator has responsibilities related to other state-funded health IT initiatives (13 of the 23 states) and additional responsibilities related to health IT (10 of the 23 states). These responsibilities include administration of the state Medicaid program and operations within the state departments of health or public health. **HIT Coordinators note that the primary advantage of having broader responsibilities within state government is the ability to gain the participation of other state agencies or programs in the State HIE Program and greater overall authority associated with their responsibilities**. **The primary disadvantage reported is decreased involvement in and knowledge of the technical aspects, implementation, and day-to-day operations of the state HIE efforts.**

Section II. Stakeholder Engagement

State HIE leadership report that state Medicaid agencies (23 of the 27 states), state public health departments (20 of the 27 states), and hospitals (19 of the 27 states) are the most active stakeholders in state HIE planning (Exhibit 1). Local HIOs are involved, where applicable, but are not present in

every state. Other stakeholders such as safety-net providers including federally qualified health centers, critical access hospitals and insurers and employers are involved to a lesser degree.

Exhibit 1. Percent of States/SDEs with "Heavy" Stakeholder Involvement in HIE Planning, by Type of Stakeholder (n=27)

STAKEHOLDER	PERCENT OF STATES
State Medicaid	85.2%
State Public Health Department	74.1%
Hospitals	70.4%
Local HIOs	48.2%
Critical Access Hospitals	44.4%
Federally Qualified Health Centers	40.7%
Payers (e.g., insurers and employers)	37.0%
Integrated Delivery Systems	25.9%
Integrated Practice Associations	25.9%
Laboratories	22.2%
Pharmacies	18.5%
Independent Practices	11.1%
Stand-alone Radiology/Imaging	8.0%
Behavioral Health	7.4%
Consumers	7.4%
Local Public Health Agencies	3.7%
Long-term Care Facilities	3.7%

Source: eHI Grantee Survey and Approved Strategic and Operational Plans*
* Approved Strategic and Operational Plans were reviewed for 3 states that did not respond to this question on the eHI 2011 survey.

Thirteen states (48%) are collaborating with Medicaid by incorporating Medicaid data into statewide HIE, and eight states (30%) are leveraging the Medicaid provider directory to establish statewide directories (Exhibit 2). Ten states (37%) are also collaborating with Medicaid on provider outreach and education, as well as the State Medicaid HIT Plan (SMHP). Nine states (33%) plan to use Medicaid funding to support aspects of Health Information Organizations (HIOs), three of which (11%) are specifically leveraging 90/10 Medicaid monies to fund activities related to Medicaid HIE. While most states report strong coordination and collaboration with Medicaid agencies, Medicaid budget constraints and replacement of the Medicaid Management Information System (MMIS) impede their progress.

Exhibit 2. State Collaboration with Medicaid (n = 27)
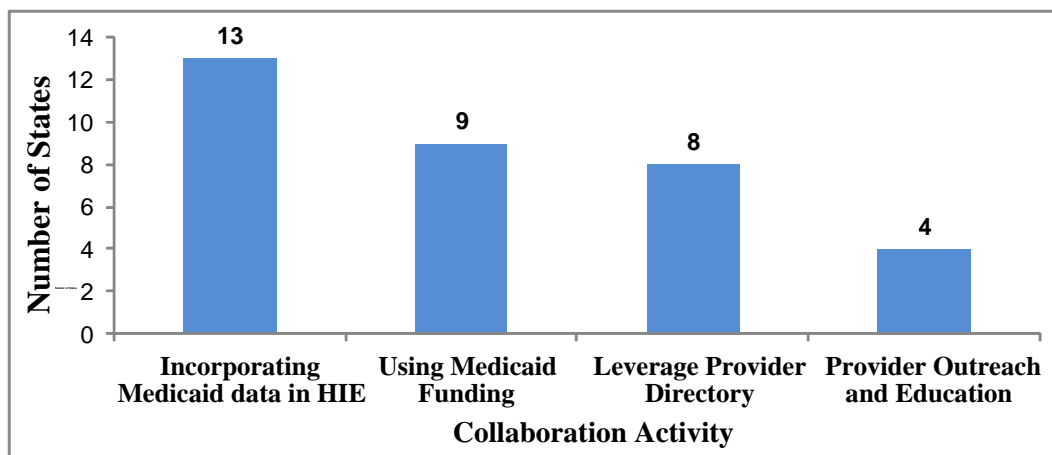
Sources: State HIE Leadership Discussions and Approved Strategic and Operational Plans

In their partnerships with state Public Health departments, states are focused on meaningful use-related public health activities, including immunization reporting (15 of the 27 states), electronic transmission of reportable lab results (12 of the 27 states), and, to a limited degree, syndromic surveillance (5 of 27 states). For both immunization reporting and reportable lab results, 12 of the 27 states report they plan to establish centralized services. Two states have already initiated pilots using direct messaging standards, while most states are in the planning or early implementation phase of public health reporting.

States report that they have less involvement with consumers and trading partners, in particular laboratories and pharmacies. Finally, although they consider these stakeholders as important for HIE efforts, two states report difficulty in engaging providers that are ineligible to participate in the Meaningful Use program (e.g., long-term care and behavioral health providers).

The majority of states report a significant level of collaboration with the REC(s) and REC representation on their advisory council and workgroups. Eight of 27 states have multiple REC grantees, and two states have four REC grantees serving their state. For six states, the recipient of the state HIE and REC funds is the same. Of these six states, three share the same leadership between both entities. States' find tremendous value in having the state HIE organization and the REC located within the same entity. This facilitates strong collaboration and allows leaders of these entities to easily align their work. In particular, co-location makes it easier to coordinate REC and HIE efforts to assist providers in meeting meaningful use requirements. Other areas of coordination include provider outreach and communications, regular meetings between the two entities, and use of the REC as a source of data on provider electronic health record (EHR) and HIE adoption plans. Contributing factors to effective collaboration with a REC include co-

> "It's amazing what a difference the REC can make to hold the small practices' hand and help them get to a comfortable way. And then the handoff is seamless to the HIO."
>
> --HIT Coordinator explaining the importance of aligned objectives between the REC and State HIE program

location of the REC and HIE organization (six of the 27 states), shared leadership between the two programs (three of the 27 states) and a prior relationship between the State HIE entity and the REC. Only two states have executed a technical assistance contract with a REC in their state.

The majority of states are in the early stages of developing and implementing their consumer engagement strategies. State plans for consumer engagement activities were classified as minimal, moderate, or detailed (Exhibit 3). A "detailed" consumer engagement plan discussed objectives, goals, and barriers for engaging patients and consumers, addressed a consumer engagement approach and rationale, and highlighted steps or a timeline for achieving consumer engagement. Only four of the 27 states provided enough detail for their plans to be considered "detailed." The largest proportion of states (11 of the 27 states) provided minimal or no detail in their plans for consumer engagement. Seven states have a moderate level of detail in their consumer engagement plan; four provided detailed plans, and five did not address consumer engagement at all.

Exhibit 3:   Level of Detail in States' Consumer Engagement Plans (n=27)
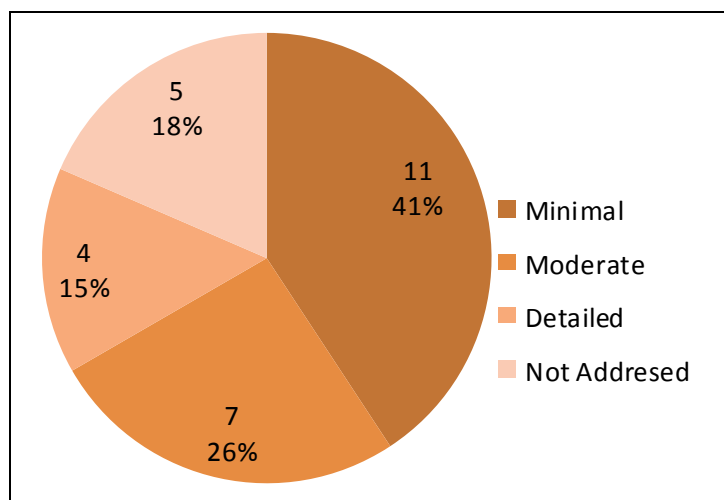
Sources: State HIE Leadership Discussions and Approved Strategic and Operational Plans

Education and outreach is a cornerstone of many states' consumer engagement plans. Discussions with state leaders and review of state plans both emphasized education and outreach as a critical component of consumer engagement. Proposed activities include: public meetings, webinars that involve a broad group of stakeholders, dissemination of educational materials (booklets, pamphlets, flyers and online materials for consumers), and posting meeting materials on the internet. A few states regularly invite feedback from consumers and providers through focus groups and with public comment periods for significant/annual updates to their strategic plan. Nine of the 27 states have consumer advisory groups and consumer engagement workgroups composed of representatives of consumer advocacy organizations and individual consumers/patients to ensure consumer perspectives are represented in the State HIE Program.

Section III. Technical Approach

The technical model refers to both the organizational framework and underlying support services that will enable HIE to take place.

The majority of states (15 of 27) are using a combination of HIE technical approaches and characterize their technical model as "mixed." Within their Strategic and Operational Plans, a few states report that they are pursuing single statewide health information organization HIO (7 of the 27) or connecting the nodes (5 of the 27) approach. During discussions, states reported using a 'mixed' model approach for a variety of reasons: (1) they may be pursuing a dual approach of bolstering local HIOs and establishing central services; (2) to pursue different approaches in different parts of the state; or (3) to pursue both a short- and long-term strategy to enable HIE. States with small populations and/or few local HIOs report pursuing a more basic model in the short-term to allow them to rapidly offer HIE capabilities so that providers have at least one option to meet meaningful use requirements.

The strategic model classification, as described by ONC, is comprised of four models. The elevator model is described as "rapid facilitation of directed exchange capabilities to support Stage 1 meaningful use." The capacity-builder model features "bolstering of sub-state exchanges through financial and technical support, tied to performance goals." The orchestrator model is a "thin-layer state-level network to connect existing sub-state exchanges." And the public utility model describes states where "statewide HIE activities are providing a wide spectrum of HIE services directly to end-users and to sub-state exchanges where they exist."[v]

States report that they see variations in their approach relative to the ONC classification of strategic approaches,[vi] since they are pursuing hybrid approaches. For example, while the orchestrator model describes a "thin-layer, state-level network," many states pursuing this model provide a more sophisticated set of central 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)[3], a Master Patient Index (MPI) and/or a record locator service (RLS). Additionally some states, particularly those with large populations, report that they are assessing how certain core services should be consolidated either centrally or regionally and promote local HIO's to focus on value-added services such as quality reporting and analytics.

The plurality of states (26 of 27) plan to provide a range of technical services. The most common service planned or offered to support statewide HIE is clinical summary record exchange (56%), followed by patient matching services (48%) and provider directories (48%) (Exhibit 4). The high prevalence of clinical summary record exchange is likely driven by its inclusion as one of the three priorities for information exchange for the State HIE Program[vii], and patient matching is seen as a key capability required to enable advanced clinical record exchange. The third most common service that is or will be offered is provider directories, which may augment directed messaging in some states. The next two most common services focus on public health reporting and public health services. These findings suggest that states are, to a great extent, focusing on the gaps in existing information exchange.

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[3] (LOINC) is a standard that facilitates the exchange and pooling of laboratory tests for clinical care, outcomes management, and research

Exhibit 4. Most Common HIE Services (N = 27)



Most Common HIE Services
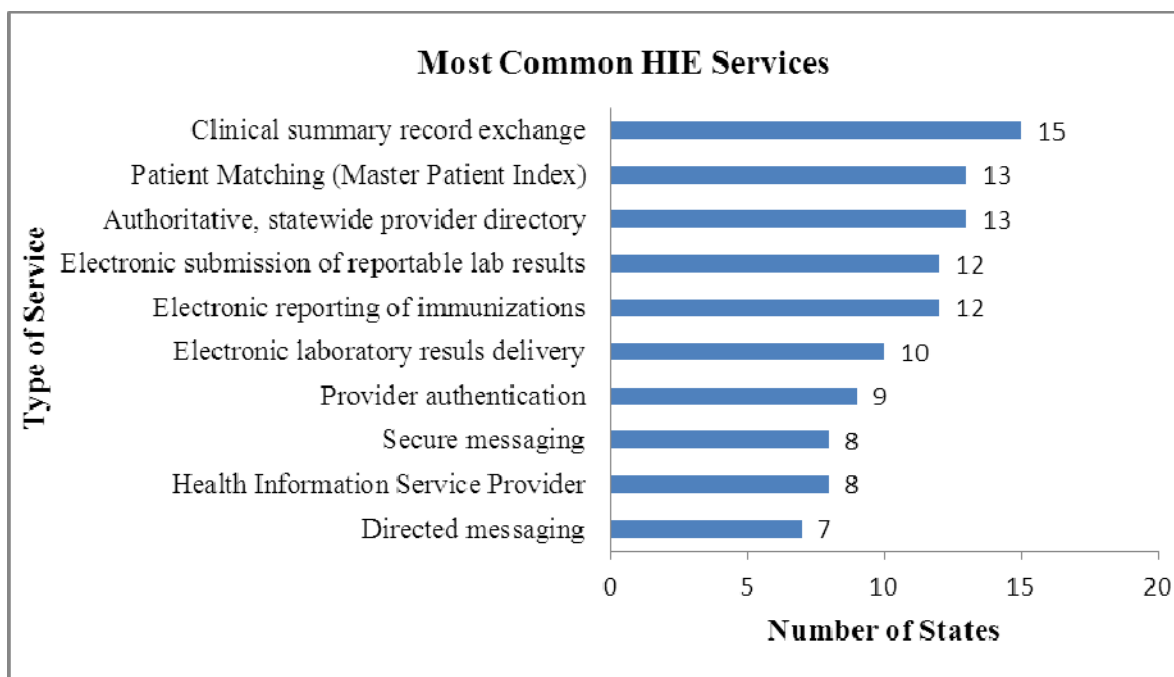
Note: At least 6 states had to report the service for it to be included in the figure. *Source:* eHI Grantee Survey

The most common reasons that influenced states choice of technical model are the level of community involvement in HIE (75%), the population of the state (71%), and location of population (rural vs. urban) (67%) (Exhibit 5). Other factors that appear to strongly influence the choice of technical model include the presence of established HIOs (63%) and level of HIE activity at baseline (58%). Additionally, states report that they sought less tangible factors that influence state selection, such as flexibility, both in terms of stakeholder involvement and the ability to adapt over time as new technologies emerge. States also sought to pursue models that were least disruptive to existing relationships and regulations in order to make their efforts least threatening. This approach is consistent with the guidance provided in the ONC HIE Program Information Notice – 001 that states leverage existing information exchange activities when developing their strategy to enable HIE.[viii]

> "We didn't want to hinder current activity and development that was currently underway by pushing something on top of it or pushing it out of the way."
>
> -- Discussant describing philosophy behind selection of a technical model

Exhibit 5. Factors Ranked as Important in Influencing States/SDE Approach Toward HIE (n=24)
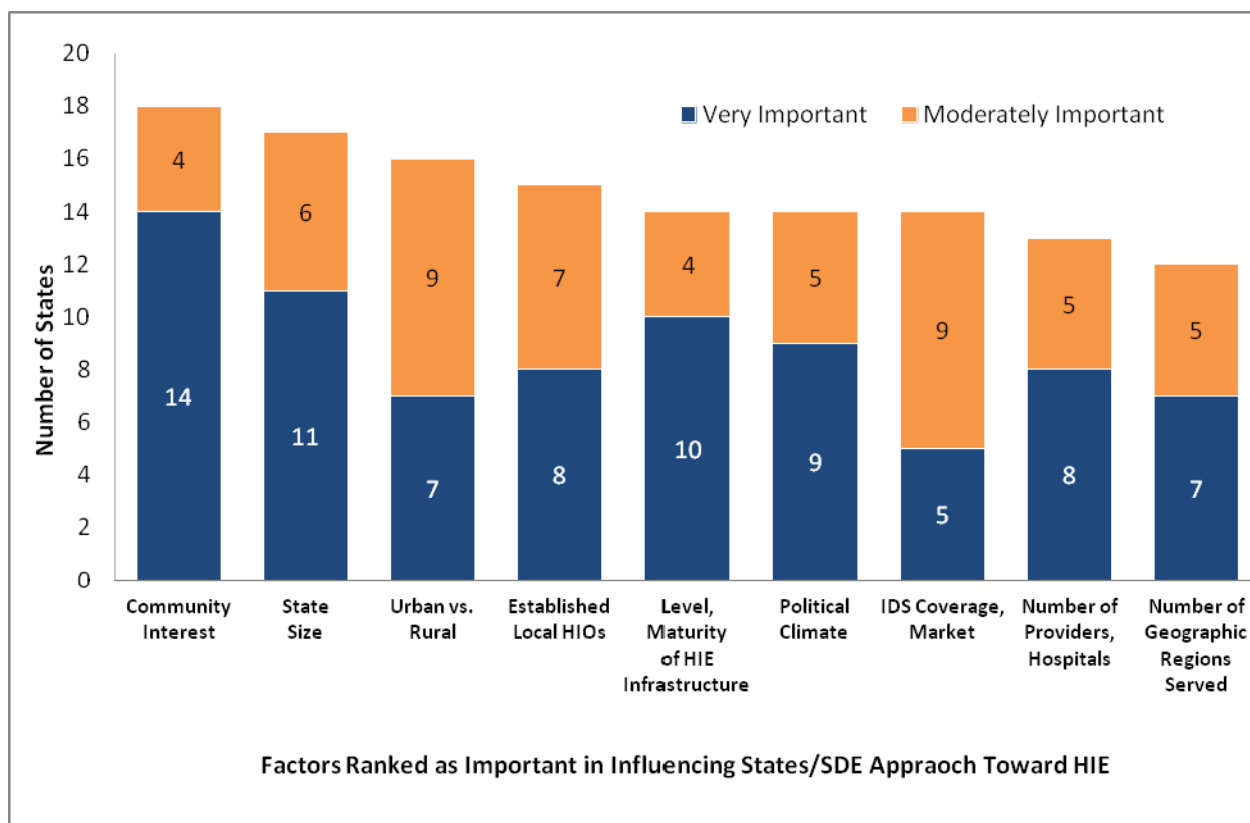
Source: eHI Grantee Survey

States almost universally recognize the importance of Direct secure messaging as a strategy to quickly enable exchange by enhancing data transport, but range in how concrete their plans are to leverage it (Exhibit 6). In addition, there is variance in the extent to which Direct is at the core of states' approaches to enable exchange. Twenty-two of the 27 (82%) states involved in the discussions report plans to use Direct and thirteen of these report their planned approach. Among these thirteen of the 22 states, six of the 13 states (46%) plan to serve as the Health Information Service Provider (HISP) [4] or provide core services for a HISP and another six of the 13 states (46%) plan to certify or qualify commercial HISPs. Nine of the 22 states (41%) that are planning on using Direct have not identified their approach as of yet, according to information obtained through the eHI Grantee Survey and State HIE Leadership Discussions.

Nine of the 22 states (41%) commented that they lacked concrete plans for Direct because it emerged after their model was selected; they report feeling unsure about how to make Direct successful due to its

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[4] 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

nascence and the lack of industry experience. These concerns have been largely resolved as more information about Direct was made available and stakeholders found ways to leverage Direct as a complementary strategy to help achieve some of the goals of the State HIE Program. In our state HIT/HIE leadership discussions, eight of 22 states are hesitant to rely too heavily on Direct because they felt that it does not enable the robust exchange they are aiming to build.

Leadership is also concerned that it will interfere with query-based exchange (either by introducing confusion or engendering stakeholder reliance on it such that they decrease support for more robust exchange). There is concern that Direct would not enable providers to query patient data at a community level in order to build a more comprehensive clinical record. This sentiment is particularly true among states with more mature HIE. It is noteworthy that Rhode Island and Maine have adopted technical approaches that overcome the potential limitation of Direct not supporting robust exchange; these states use Direct for provider-provider exchange and to route clinical summary records to a centralized repository. Finally, two states report that the state will finalize their approach based on the experiences of their local HIOs with Direct.

> "We do recognize that there is a use case for one-to-one exchange of information and the Direct standards help facilitate the use of EHRs to facilitate that one-to-one exchange, there is no harm in encouraging people to look at that and see if it is valuable to them."
>
> --HIT Coordinator on state and industry interest in Direct

Exhibit 6: For States/SDEs Planning to Use DIRECT, Type of Role(s) for States Facilitating Use (n=22)
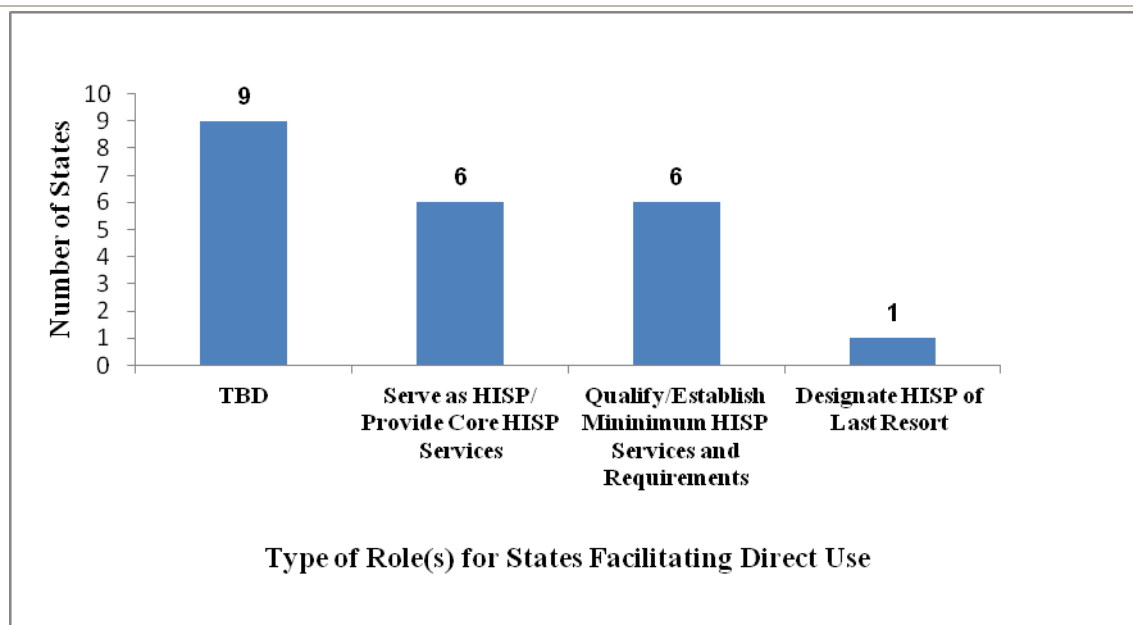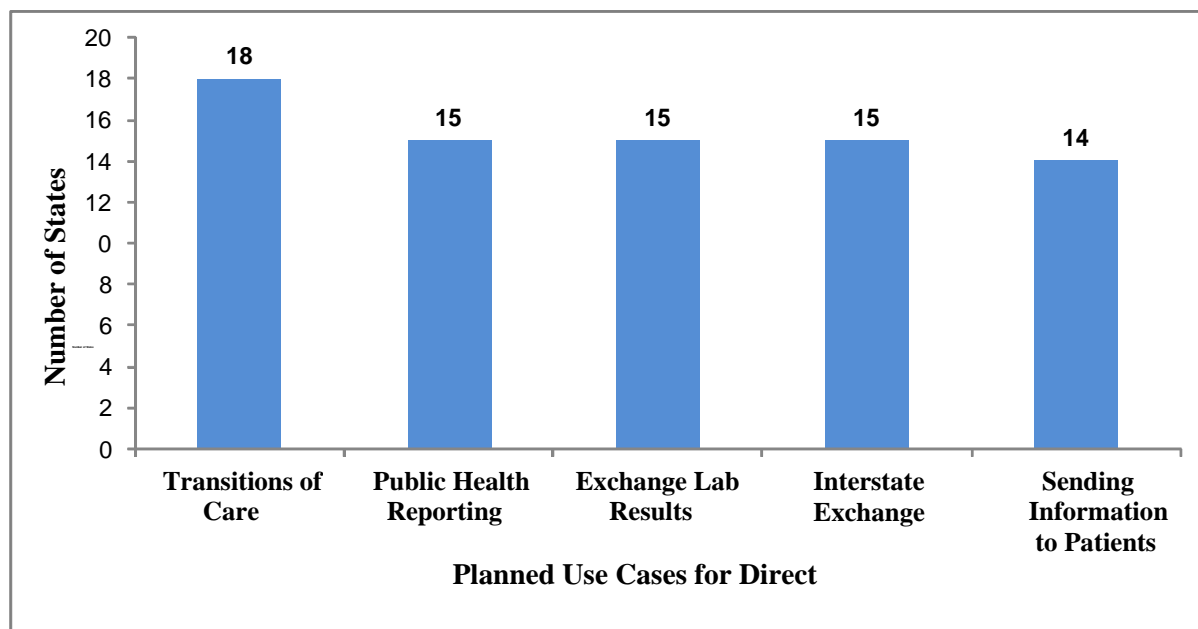

Source: eHI Grantee Survey and State HIE Leadership Discussions. *State discussions were reviewed for 4 states that did not respond to this question on the eHI 2011 survey.*

States vary in the "use cases" in which they are applying Direct (Exhibit 7). Transitions of care is the most typical use case reported in 18 states (82%). Other top use cases include: public health reporting in 15 states (68%), exchange of lab results in 15 states (68%), interstate exchange in 15 states (68%), and

sending information to patients in 14 states (64%). Amongst the states planning to use Direct, almost all plan to use it for a wide array of use cases. Some states reported that while they are moving ahead with their strategy for Direct, they were unsure about the demand for these services from HIE stakeholders.

Exhibit 7. Planned Use Cases for Direct (n=22)

Source: eHI Grantee Survey and State HIE Leadership Discussions*
*state discussions were reviewed for 4 states that did not respond to this question on the eHI 2011 survey.

Section IV. Program Information Notice (PIN) Priorities for Exchange

The Program Information Notice (ONC-HIE-PIN-001)[ix], issued July 28, 2010, prioritized three HIE capabilities: e-prescribing, sharing of patient care summaries across unaffiliated organizations and receipt of structured lab results.

States selected providing translation services most often (11 of the 24) as their approach to enable exchange of laboratory information (Exhibit 8). State plans indicate that a number of states are enabling lab reporting by providing translational services to LOINC, and developing structured formats for recipients of lab results such as primary care providers. Some states reported that the costs and expertise required for LOINC mapping is a big challenge for many labs so enabling these services is likely to produce immediate value. Other strategies include EHR interface support (9 of 24) and ensuring that standards for data transactions, i.e., lab ordering and results reporting are identified and communicated to labs and EHR vendors.

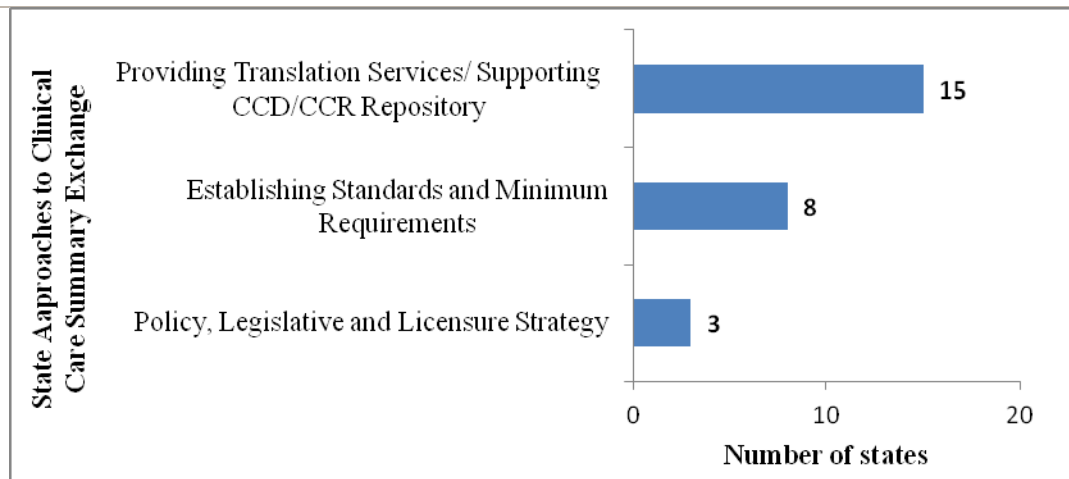**Exhibit 8.** State Approaches to Enable Lab Exchange (n= 24)
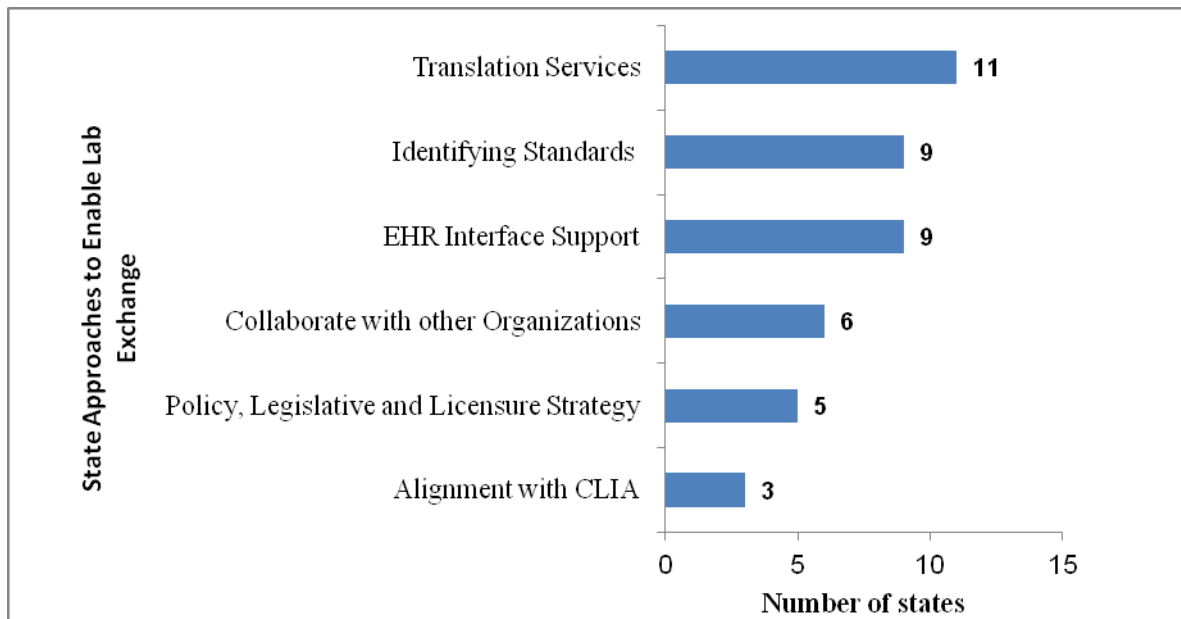
Note: At least 3 states had to report the approach for it to be included in the figure. *Source:* Approved Strategic and Operational Plans

States report limited exchange of clinical care summaries between unaffiliated organizations and are considering a variety of technical approaches (Exhibit 9). Reasons cited for limited exchange include inadequate functionality of EHRs and lack of adoption of current standards. Fifteen of 25 states report they will provide translation services and/or a CCD/CCR repository to enable clinical care summary exchange. Eight of 25 states plan to establish minimum standards and requirements for the exchange of clinical care summaries between unaffiliated organizations.
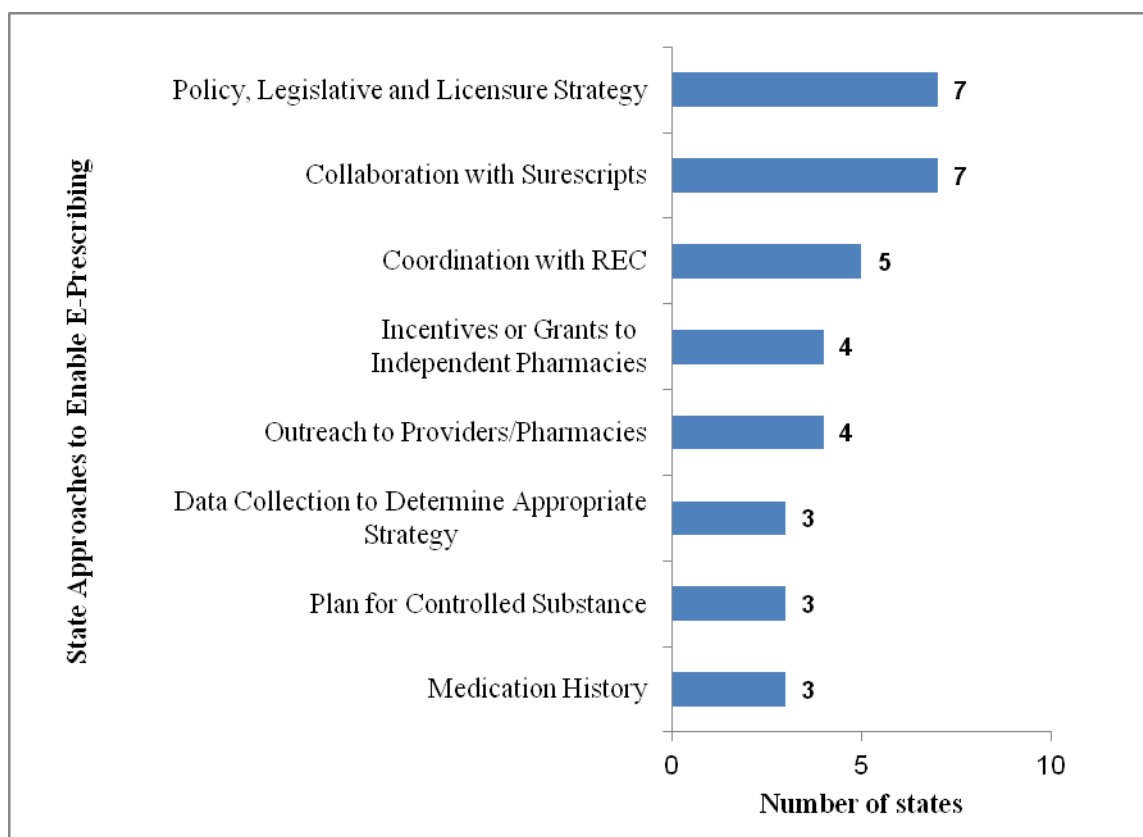
Exhibit 9. State Approaches to Enable Clinical Care Summary Exchange (n= 25)

Note: At least 3 states had to report the approach for it to be included in the figure. *Source:* Approved Strategic and Operational Plans

State approaches to e-Prescribing are focused on using various policy and legislative levers Exhibit 10). States report that for the most part, the necessary infrastructure to support electronic transmission of prescriptions is already in place. Common barriers for e-prescribing include transaction costs and charges to connect to Surescripts. Therefore, states are largely focused on using policy and legislative levers (7 of 25) or facilitating collaboration with Surescripts (7 of 25). Some states discussed policy changes to require providers to use e-prescribing to participate in health plans and legislative approaches to allow e-prescribing of controlled substances. Other strategies include coordination with the REC or incentives to independent/community pharmacies.

**Exhibit 10.** State Approaches to Enable E-Prescribing (n=25)

Note: At least 3 states had to report the approach for it to be included in the figure. *Source:* Approved Strategic and Operational Plans

Section V. Privacy and Security

States most commonly selected an 'opt-out' consent approach (13 of 27 states). Although many states are enabling point-to-point HIE solutions that generally do not require consent, most states have planned for HIE consent options. States that selected an opt-out approach report that this is the best way to secure participation from the largest number of patients in information exchange and to avoid the

challenges associated with obtaining individual patient consent. Seven of 27 states utilize an opt-in consent approach (Exhibit 8), and often justify their choice by citing state laws that require patient consent prior to exchange of information. In addition, some "opt-in" states see their model as a mechanism to assure patients are informed at the outset about the opportunities to use health information to improve patient care. Also, because federal regulation (Confidentiality of Alcohol and Drug Abuse Patient Records, 2000)[x] requires consent for disclosure of substance and alcohol abuse information maintained in connection with the performance of any federally assisted alcohol and drug abuse program and some state laws require consent for especially sensitive information such as behavioral, HIV/AIDS, or mental health, the opt-in consent model removes the necessity to filter this information. Three states (11%) are using a hybrid approach where an opt-out consent model is applied for all information except sensitive data (such as mental health and HIV/AIDS information), for which they use an opt-in approach. These states selected a hybrid approach because existing statutes impose higher privacy standards than those imposed by the HIPAA regulations. Finally, in three of the 27 states, the individual HIO or trading partner determines consent and there is no single statewide consent model. In addition, many states are considering point-to-point HIE solutions that generally do not require patient consent. States carefully considered consent approaches and chose the best fit for their environment.

Exhibit 11. State Consent Models (n=27)
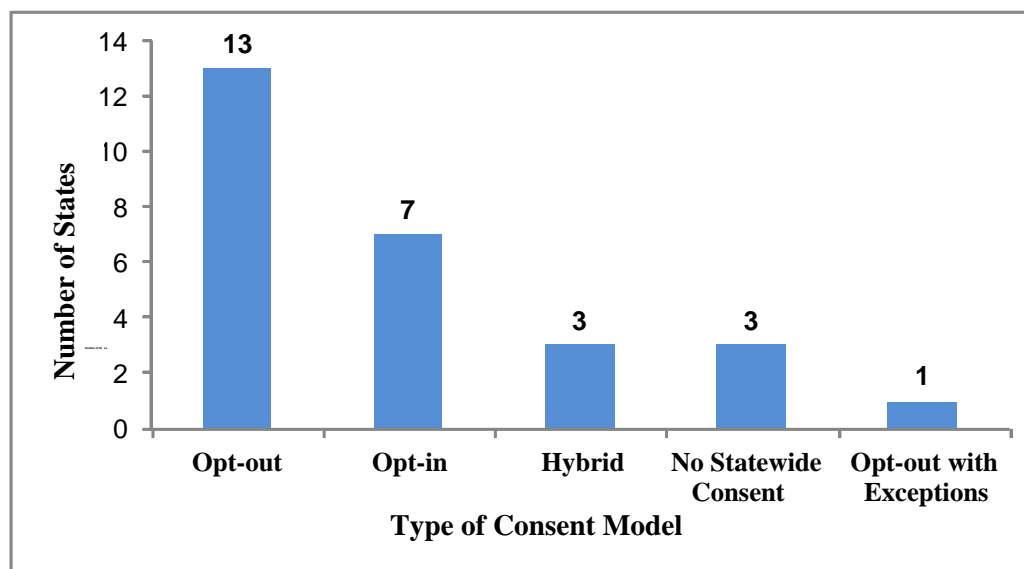
Sources: State HIE Leadership Discussions and Approved Strategic and Operational Plans

States are acutely aware of the importance of assuring the security and privacy of HIE, but are focused primarily on setting up or enabling the technical structure for HIE. As a result, states have not yet, for the most part, fully implemented a state-level privacy and security framework. States have also made significant progress in understanding regulatory barriers to HIE and are in various stages of addressing this. Four Health IT Coordinators explicitly note that, although it was important to ensure adequate policies and practices were in place for Protected Health Information (PHI), patients are

generally not concerned about this issue and, indeed, many were under the impression that exchange of health information was already occurring.

Section VI. Implementation

States are in the early stages of implementation. The vast majority of states report that they are in the process of implementing their approved plans (24 of the 27) and issuing, selecting, or negotiating vendor contracts. States have selected their approaches to enabling statewide exchange. A few states also report that their implementation timeline has been affected by the delay in approval of the state plans.

States are making good progress with leveraging policy levers and removing legal and regulatory barriers to HIE. Thirteen of 27 states are in the process of passing legislation related to HIE or have already done so while eight states are in the process of identifying laws to be changed. States are pursuing legislative changes in the following areas: patient consent, data ownership and storage, data sharing agreements, enforcement, changes in liability laws, e-prescribing for controlled substances, third party audit of the exchange, exchange of behavioral health information, laboratory exchange, access to newborn data, mandating provider participation in the statewide HIE and addressing HIPAA as it pertains to disclosure of PHI. Six of 27 states report no issues with current laws and have no plans to pass new laws in support of health information exchange.

States appear to be encountering numerous challenges in enabling HIE in their settings. The following challenges were mentioned by a number of the participants.

- *Low EHR Adoption Rates.* Fifteen states (56%) reported a lack of EHR adoption, particularly low penetration of EHRs in small/solo physician practices as a major issue. States that have larger rural populations also cited limited EHR adoption as a concern. Although states reported that incentive payments appear to be fostering interest in EHR adoption, providers are focusing on acquiring EHRs and not on HIE at the moment, which is more complex and costly. In addition, some states reported that behavioral health and long term care providers have been slow to adopt EHRs and it has been particularly difficult to foster interest in EHR adoption and exchange amongst these stakeholders.
- *Financial Challenges.* For thirteen states (48%), securing the necessary resources for enabling HIE and developing a viable sustainability model was a challenge. The availability of funding during the cooperative agreement period was also a challenge for a few states that experienced delays in approval of their plans and release of implementation funds. Additional challenges include access to and use of Medicaid MMIS and Incentive funding to promote program integration, and difficulty in obtaining federal grant funding for SDEs. States also cite difficulties in using federal grant funding at the state level given state procurement and financial administrative issues.
- *Competing Priorities for State Leadership.* Twelve states (44%) are facing competing priorities; in particular, states note other demands due to health reform, insurances exchanges, Beacon community activities and other growing demands generally on state budgets compromise the level of resources they have to focus on this initiative.

- *Addressing privacy and confidentiality issues.* Seven states (26%) reported concerns that the proposed modifications to the HIPAA rule to implement the Health Information Technology for Economic and Clinical Health (HITECH) Act provisions had not yet come out. Some states were particularly concerned about how the final regulations will be interpreted and whether there would be a conflict between the federal requirements and the approach selected by the state.
- *Stakeholder Collaboration.* While most states did not perceive any obstacles in engaging with stakeholders, six states (22%) reported maintaining their engagement has been difficult. In particular, keeping dominant providers (e.g., Integrated Delivery Networks) engaged was an issue. Many Integrated Delivery Networks, are already exchanging data both in the inpatient and ambulatory setting, and are capable of meeting early stage meaningful use requirements regardless of the state HIE project. States also cite difficulty gaining the attention of small/solo providers and familiarizing them with the advantages and opportunities of HIE. Two states (7%) reported that it was difficult to get providers not incented under the EHR incentive program, such as long-term care and behavioral health providers, to participate in the State HIE efforts. Finally, establishing the priority of HIE among other competing federal and state priorities impacting stakeholders is a continuing challenge.

The majority of states are primarily focusing on implementing their approved plans and are very early in the process of developing concrete sustainability plans. Although states were specifically asked to comment about their approach to ensuring sustainability of information exchange and not sustainability of a particular entity that is enabling/providing HIE services, states almost invariably focused on the latter. The majority of states are only creating plans to sustain statewide HIE, while at least four states acknowledge that their sustainability planning will also address how to ensure that the local HIOs are also sustainable in the future. Fifteen states (56%) report concerns about the availability of funding after the program period. In developing their sustainability plan, states appear to be exploring the full range of potential payers– state and federal government, payers, hospitals, and providers– to provide funding to sustain HIE efforts in the future, they are planning their programs to offer the most value to stakeholders in order to ensure sustainability. The challenges that states are facing in creating and implementing sustainability plans are numerous. In some states, the HIE environment is still new and susceptible to change, thus making it difficult to anticipate who the stakeholders will be or what technologies will exist in the future. Furthermore, since there is no state yet that has successfully implemented a comprehensive statewide HIE approach that is sustainable, there are no models that describe the full costs of enabling and/or operating statewide HIE or that suggest approaches that are most likely to result in long-term sustainability.

> "Sustainability comes from creating value. Using the funding from ONC alone will not get you there."
>
> --HIT Coordinator discussing concerns with sustainability planning

Conclusions

Findings from our review of 27 states, one year and six months since the inception of the program, suggest that in most cases, states are beginning to implement their approved plans and distinct and evolving approaches are beginning to emerge.

States have selected a state-led, SDE-led, or SDE-like approach to enabling statewide HIE. In addition to standing-up formal governance and policy structures, states are also involving a variety of stakeholders in their planning, implementation, and sustainability efforts, including: state Medicaid, department of public health, RECs, and consumers.

States are choosing their individualized technical model based on a variety of factors, such as, level of community interest in HIE, location of the population, and the size of the state. Most state models use a combination of HIE technical approaches and tend to characterize their technical models as "mixed." States are also enabling a variety of services, including electronic record sharing, clinical reporting systems, and patient-provider messaging. Many states have plans to use Direct. While some of the states have their implementation approach selected, there are a number of states that have not yet decided.

The majority of states anticipate implementing an 'opt-out' consent approach with the belief that it is the best choice for increasing the amount of patient data being exchanged. In addition to developing consent models, states are also reviewing national and state legislation related to exchanging personal health data to ensure that the selected approaches are compatible with the law. States have made good progress with removing legal barriers to information exchange.

States are just getting underway with the implementation of their approved plans. In general, states report that implementation progress has been slower than initially anticipated.

The NORC evaluation team will continue to study these approaches, how they evolve, implementation progress and identify the factors that lead to faster and more robust exchange over time.

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[i] Office of the National Coordinator. (2009). *American Reinvestment and Recovery Act of 2009 – Title XIII – Health Information Technology, subtitle B – Incentives for the Use of Health Information technology, section 3013 – State Grants to Promote Health Information Technology, State Health Information Exchange Cooperative Agreement Program, Funding Opportunity Announcement.* Department of Health and Human Services.

[ii] Department of Health & Human Services (HHS) Office of the National Coordinator for Health Information Technology (ONC). (February 2011). State HIE Strategic and Operational Plan Emerging Models

[iii] Agency for Healthcare Research and Quality Archive. (2004). *State and Regional Demonstration Projects in Health Information Technology (AHRQ-04-0015).* Retrieved from http://archive.ahrq.gov/fund/contarchive/rfp040015.htm

[iv] Blumenthal, D. (2010). *Requirements and Recommendations for the State Health Information Exchange Cooperative Agreement Program.* Washington, DC: Office of the National Coordinator for Health Information Technology. Document Number: ONC-HIE-PIN

[v] Department of Health & Human Services (HHS) Office of the National Coordinator for Health Information Technology (ONC). (February 2011). State HIE Strategic and Operational Plan Emerging Models

[vi] Ibid.

[vii] Blumenthal, D. (2010). *Requirements and Recommendations for the State Health Information Exchange Cooperative Agreement Program.* Washington, DC: Office of the National Coordinator for Health Information Technology. Document Number: ONC-HIE-PIN-001

[viii] Ibid.

[ix] Ibid.

[x] Confidentiality of Alcohol and Drug Abuse Patient Records, 42 C.F.R. § 2 (2000)