HOW STATES PROMOTE AND GOVERN HIES AND ENGAGE THEM TO SUPPORT PUBLIC HEALTH

A FOUR-PART RESEARCH PROJECT
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Introduction to the Research Project

Abstract

We interviewed 52 states and territories to understand how state governments have engaged with state and subregion health information exchanges (HIE) within their jurisdictions. We investigated the ways states participate in governance of these HIEs, strategies states use to promote exchange activity, and ways the state departments of health are leveraging HIEs for public health purposes. We found significant state involvement in HIE activity, some prompted by the response to the COVID-19 pandemic. Yet, approaches among the states differ significantly. Here we introduce the four papers, which are the output of the research.

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Methods

We conducted video interviews with individuals who are familiar with the HIE and interoperability efforts in their jurisdiction. Respondents came from HIE organizations, state agencies, and technology vendors. The research captured information from all 50 states, Puerto Rico, and the District of Columbia. The categories of inquiry included: HIE landscape, HIE enablement, governance, mandates, and public health engagement. Interviews lasted 30 to 45 minutes and were recorded and transcribed to assist in subsequent coding. Follow-up questions were asked via email as necessary, and all references to specific states were verified with respondents. We interviewed a total of 78 people.

Introduction

The exchange of health records happens in many ways in support of clinical, public health, and payment processes, generally enabled through robust standards such as those propagated by HL7[1]. Although nationwide commercial networks exist, policy and health care leaders in nearly every state[2] have taken steps to promote HIE infrastructure that specifically serves their state or a subregion. Nearly all of these HIEs are based on a nonprofit business model or housed within a department of state government. They receive some government funding and, while their capabilities may overlap with nationwide networks, the HIEs also serve interoperability purposes that are not otherwise well supported in the normal course of health care delivery.

Our research aims to better understand the relationships between states and their HIEs, and our focus was the interaction between state leaders, public health agencies, and the HIEs. We sought to understand if and how state government was promoting or enabling this exchange

[1] Health Level Seven International (HL7) is a not-for-profit standards development organization for the interoperability of health data. https://www.hl7.org/about/index.cfm?ref=nav

[2] For readability, we use the generic “states” to include Puerto Rico and the District of Columbia in this and the other papers.

work. We examined governance of the exchange organizations, especially levers state government used to influence or regulate the HIEs. In some states, HIEs are becoming infrastructure on which public health agencies rely. We wanted to understand the extent to which this is happening and when state authority to mandate health data reporting is being applied.

While many surveys of the HIE industry have been conducted, these have typically focused on specific organizations and their services. Our unit of investigation was each state, whether it is served by one primary HIE, several, or some other arrangement. Prior surveys have often used online questionnaires for self-reporting, and there is reason to question the accuracy of results when the questions are open to interpretation. We sought to interview individuals, such that clarifying questions and discussion could help us improve the consistency of responses. The output of the process is four papers as described below.

Our research was specific to states' interaction with their own statewide HIE or regional HIEs within a state. It is important to point out that national interoperability networks, electronic health record (EHR) vendors, venture-backed startups, health systems, and administrative networks are also providing many important HIE or HIE-like services within states. Our analysis did not evaluate how these services are evolving or impacting the role of state-based HIEs, but the presence of multiple types of organizations in the interoperability ecosystem is noteworthy.[3]

The researchers would like to thank CRISP, the state designated HIE in Maryland, which funded the time and effort required to conduct this project. Civitas Networks for Health, the trade association to which most HIEs belong, was very helpful in identifying potential interviewees within each state. David Horrocks would like to thank his dissertation advisor, Professor Laura Morlock of the Johns Hopkins Bloomberg School of Public Health, for her extensive advice.

Paper 1: Methods States Use to Organize and Promote Health Information Exchange

Approaches states take to health data interoperability vary significantly. There does not seem to be model legislation or a specific formula that has been repeated among policy makers, so each state is unique. Still, there are similarities and best practices, and we sought to group states in one of four categories based on common elements of their approach. The aim was to create a conceptual framework that helps to characterize the work happening across the country.

Paper 2: Using Health Information Exchange to Support Public Health Agencies

Many states are relying on HIEs to augment public health infrastructure. This support ranges from assisting clinicians with mandatory reporting to operating disease registries on behalf of the department of health. Many HIEs have described new engagement with their public health agencies as they support the response to the COVID pandemic. We wanted to develop a basic understanding of public health support states receive from HIEs and to highlight illustrative examples of this work.

[3] Everson J, Patel V. **Hospital's adoption of multiple methods of obtaining outside information and use of that information**. JAMIA, May 2022.

Paper 3: Five Example States That Promote Health Information Exchange

As noted, the approaches among states and the interoperability outcomes both vary significantly. Paper 3 was written to highlight a selection of states with positive outcomes. As one measure of success, we surveyed a dozen leaders in the HIE industry — HIE Executive Directors, technology vendor executives, and HIE consultants — asking them each to name five states that they consider leaders in the industry. Our criteria were states that have broad connectivity; in which clinicians, payers, and public health agencies are receiving strong interoperability services; and that are innovative. Based on these responses, we profiled five states: Arizona, Indiana, Maryland, Michigan, and Nebraska. While the selection methodology has limitations, the summaries of each state provide examples of interest.

Paper 4: Incentives and Mandates States Use to Promote Health Information Exchange

In the federated system of the United States, most public health authority is invested in states. Registries of reportable conditions, such as for infectious disease, are compiled using the authority states possess to require that healthcare providers submit certain data about their patients. States also use legislation, regulation, and contract authority to incentivize or mandate that organizations participate in an HIE. Our paper explores the methods used to accomplish that aim.

Conclusions

Our research documents significant state engagement with and support for HIEs, with a growing reliance on HIEs to support public health purposes. The depth and methods of engagement by states do vary significantly but can be categorized as one of four broad approaches. Policy makers, public health agencies, and other healthcare leaders should examine the outcomes achieved and methods of promotion used in peer states. Federal policy makers who are examining ways to modernize public health infrastructure should take note of accomplishments at the state level.

Limitations

Although an interview process has advantages to a self-completed survey form, our research still relied heavily on the characterizations made by those working within the states. There could be gaps between the ways participants believe services are being used and the reality of those receiving the services. A more thorough process would compare the responses of multiple interviewees in each state, capture quantifiable service utilization numbers, and more thoroughly analyze the language of statutes and regulations.

Changing policy created another challenge for the analysis. States may have designated an organization to serve a special interoperability purpose 10 years ago, and it is sometimes a judgment call to say whether that designation continues to be meaningful. As noted, national interoperability networks, EHR vendors, venture-backed startups, health systems, and administrative networks are also providing HIE or HIE-like services within states, and our analysis did not evaluate how these services are evolving or impacting the role of state-based HIEs.

Next Steps

A maturity model of HIE services among states would be a good companion to this research, as would a closer analysis of HIE capabilities and health and health care outcomes. A "State HIE Maturity Model" could be helpful, akin to the **Electronic Medical Record Adoption Model** created by HIMSS to evaluate progress of health systems toward digital health.[4] Comparison of health and health care outcomes should also consider the level of state investment to promote or build the services. An evaluation of state spending and of federal matching dollars spent by each state could be of use.

[4] https://www.himss.org/what-we-do-solutions/digital-health-transformation/maturity-models?utm_campaign=maturity_models&utm_source=google&utm_medium=cpc&utm_term=_&adgroupid=1345093724 49&gclid=Cj0KCQjw6pOTBhCTARIsAHF23fKTWOSWzlrv9pgVV_Zf4l4qPuvh9yjGVVzaAsUwKxtQ-iOZ7UbyHdcaAuPdEALw_wcB

Appendix

A. Research Questionnaire

The research questionnaire was refined over the course of the first 10 interviews, based on responses from early respondents. Initial interviews were more open-ended, and transcripts were reviewed using qualitative research methods to find themes and to refine questions.

Governance Research Codebook v 1.2			
Question	**Code/category**	**Definition**	**Guidelines for when to use the code or not**
Landscape:			
1. Does your state have a single dominant HIE, several competing HIEs, or something else?			
	Single	One HIE is the primary focus on state engagement, even if other HIE happens such as eHealth Exchange	
	Several	More than one HIE provides significantly broad services	Not used just because SureScripts, eHX, or CMT for narrow purposes are operating in the state
	Other	Something else, including big gaps in HIE services	
2. Are other organizations providing "HIE like" interoperability services?			
	Yes/No	Generally capture other services provided by non-dominant HIEs	
Enabling Legislation or Regulation:			
1. How did your state enable HIE? Did your state enact legislation, have an Executive Order, or have a regulatory process for the creation, designation, or regulation of HIE(s)?			
	Does not actively enable	Will skip many questions below …	
	Legislation		
	Executive Order		
	Regulation		This may be in addition to regulation, so it could be two things
	Other		Could include provisions in state contracts, for instance
2. Is one or more organizations designated or specially identified in some official capacity?			

	Yes/No	This could be done in a variety of ways	
a. If yes, can multiple entities be designated?			
	Yes/No	There is a special designation or regulation, which could theoretically apply to more than one	Only counting “designated” or specially regulated HIEs
b. If yes, are there currently more than one?			
	Yes/No	Currently more than one	Does not count eHealth Exchange or SureScripts for instance, or unregulated hospital community HIEs
c. Does the designation create benefits or obligations for the HIE?			
	Yes/No and explanation	If yes, capture the benefits or obligations	Procurement goes in the question below
d. Does designation make procuring services from the designated HIE easier in some way?			
	Yes/No and explanation		
3. If legislation was used, is a designated entity named in legislation?			
	Yes/No		Yes, if an HIE is named, but not if an organization to regulate HIEs is named
4. If legislation was used, does the legislation allow for a process to choose an entity, via commission, state agency, or otherwise?			
	Yes/No		Yes, if an organization/agency to regulate or choose HIEs is named, or authority is granted somehow
5. Is there a process for promulgating regulations?			
	Yes/No		Only if the process is generally intended for HIE or interoperability, not if Medicaid regulations require something
6. Are state contracts used to place requirements on the HIE in a form that are similar to regulations?			
	Yes/No		Could be Medicaid contracts with an HIE, or something similar. Not intended to capture mandated participation in an HIE.

7. Is there a governance body other than the HIE, and if so how is that defined or shaped in law or regs?			
	Yes/No and explanation		
8. Is the organizational structure for the HIE(s) defined in the legislation, regulation, etc. (nonprofit/for-profit or within a state agency)?			
	Nonprofit / state agency / other		There are a few organizations that are "public benefit" and other nuances of nonprofit
9. Are specific organizations/agencies named to participate in the governing body, or do elected officials get to make appointments?			
	Yes/No and explanation	Yes means at least one board appointment is defined in the regs or statute to be made by government.	Does not mean the board itself has decided to appoint a government official, although knowing that is helpful
10. Does the enabling legislation, regulation, etc. define the state Opt In/Out requirements?			
	Yes/No and explanation	Could be partial or in selected circumstances — capture the details	Does not include HIPAA norms
11. Does the enabling legislation, regulation, etc. create other extra patient protections?			
	Yes/No and protections	Patient privacy such as audits, opt out, or mandatory disclosures	Does not include HIPAA norms, and should not apply if a rule is statewide for any HIO
12. Is a funding model defined in the legislation/regulation? If so, what is the model?			Not everyone who gets state money will answer yes.
	Yes/No and explanation	If yes capture the model	
13. Has the structure of the HIE(s) been adjusted along the way, through legislation or regulation?			
	Yes/No and explanation	Capture the particulars if possible. Is it becoming closer or more separate from the state?	
14. Does legislation or regulation give a state agency special rights to the data collected?			
	Yes/No and explanation		
15. Can you help us locate the relevant part of state law or regulation we discussed for reference?			
		Section of state code or register	

Mandates:			
1. Are any mandates are in place to compel providers to participate in HIE(s) in your state? (State Law, Medicaid Contract, or Other)?			
	Yes/No and explanation	If yes, record the data	Such as an ADT mandate to be in a shared savings program, or patient rosters, or provider directories
a. Which providers are included in the mandate? (payers, hospitals, clinics, behavioral health, LTC, EMS, pharmacies, etc.)			
	Describe the situation		
b. What are the terms of the mandate — how long to connect, penalties, incentives, what data must be shared to qualify?			
	Describe the situation		
2. Do your HIE(s) receive any data, or copies of data, which are collected under a government authority? (Public health reporting, EMS or Police, PDMP).			
	Yes/No and explanation	If yes, record the data	Receiving data from public health, such as case files, immunizations, PDMP, etc. Not Medicaid or Medicare claims, which is in the questions below
3. Do your HIE(s) receive Medicaid, Medicare, or state employee insurance claim data?			
	Yes/No and explanation	If yes, record the data	
Public Health Engagement:			
The following questions explore if and how the state or local Public Health departments rely on the HIE(s) in your state for services			
1. Do the HIE(s) allow public health employees access to clinical data?			
	Yes/No		
a. How frequently is that used?			
	Frequency per week	Record the frequency as number of times accessed per week	The number should not include auto-queries, but note those separately
2. Do the HIE(s) facilitate reporting from the community to public health of Labs, Syndromic Surveillance, Vaccines, or other information?			
	Yes/No and explanation	If yes, which of the examples and how extensively	This is pass-through activity

3. Do the HIE(s) combine bulk data sets, such as to enhance data for contact tracing?			
	Yes/No and explanation		This does not include individual patient data. It is data sets.
a. What data sets are combined?			
	Data sets	If yes, what date sets are combined	This does not include individual patient data. It is data sets.
4. Do the HIE(s) facilitate the state reporting to federal agencies?			
	Yes/No and explanation	If yes, what data is reported	
5. Do the HIE(s) communicate public health data back to clinicians or care managers in the field?			
	Yes/No and explanation	What data is collected? Reportable conditions, enrollments status, public health alerts, etc.	Is not about a general notice that isn't tied to a particular patient
a. What method(s) are used to communicate?			
	Methods	Alerts, portal display, secure email, etc.	
Other state services:			
1. Do your state HIE(s) operate any of these services on behalf of the state? Yes/No/Planned			
	APCD (full or partial)		
	PDMP (full or partial)		
	Bed capacity or resource tracking		
	Patient access service for a state agency		
	Disease or other public health registries		
The following section only used to understand governance, in cases when a single HIE serves as a "Health Data Utility" and the governance of that entity reflects the state's governance of its HIE efforts.			

Governance of a Dominant or Designated HIE:			
1. What is the general makeup of the governing body(ies) or board(s) that oversees the HIE(s) in your state?			
	Describe		
1b. Are the HIEs for-profit, nonprofit, or other?			
	For-profit, nonprofit, other		
2. Do the HIE(s) have formal member organizations? If so, who are the members?			
	Yes/No and members		This is for "Membership" organizations only, do not use if by convention an organization is generally consulted
3. Are the governing body members appointed, elected by the board, elected by participants, some combination, or other?			
	Member appointed	An official member of a membership corporation makes an appointment	
	Self-perpetuating	The board nominates and appoints its own new members	
	Participant elected	Elected as for Civitas	
	Other	For instance, bylaws allow the hospital association to appoint someone	
	Some combination		
4. Do you have named subcommittees performing important governance functions?			
	Yes/No and explanation	Capture the committees	
5. What is your consent model?			
	Opt In		Do not use this simply because behavioral health is opt in
	Opt Out		
	Other		
	Combination		

B. Reputational Leaders Email

Selecting states to profile in the **Reputational Leaders** paper was done through a simple survey of individuals who, in the opinion of the researchers, have a good handle on HIE activity around the country. The following email text was used to introduce the email survey to respondents. Additional context was generally repeated in a phone call from the researchers to the respondent. The request was made of HIE Executive Directors who are known to be active in industry-wide advocacy or collaboration, consultants from firms that work with many states, and trade association leaders who interact with many state HIEs.

> *As part of the research project, which I am working on, in which we are interviewing people from all 50 states, I'd like to highlight the approaches used in a few states, which are considered leaders in the interoperability space. Can you suggest to me 5 states (other than your own), which you consider to be leaders? I won't reveal whom I asked or what they said!*
>
> *The answer should be states, which have broad connectivity, in which clinicians, payers, and public health are receiving strong interoperability services, and which are innovative. I'm basically asking people in the industry who would know, to tell me based on reputation which states they believe are doing really well.*
>
> *A simple reply with 5 states is sufficient, but if you feel like telling me why you think they are strong, that's even better.*

This method of selecting leaders clearly has limitations and could be subject to bias, not least based on whom the researchers considered most knowledgeable. A more thorough process would rely on a broader set of respondents, and ideally researchers would rely on some quantitative measures to determine which states to highlight. Further, this method did not ask respondents to consider the cost effectiveness of a state's efforts in their determination. It is possible that the states selected to highlight could be receiving richer services but also paying a high price.

Still, recognizing that we would not have the time in this current round of research to address these limitations, the researchers believe there is value in highlighting states with a strong reputation among a group that is knowledgeable. Sixteen states were named by at least one respondent, but only the five states selected for profile were listed by a majority of respondents.

C. Table of Observations

Public-Private Utilities	22 states	Legislation	17 states
		Executive order	5 states
Orchestrators	7 states	State agency coordinator	4 states
		Nonprofit coordinator	3 states
State Run Services	9 states	Legislation	7 states
		Executive order	2 states
Private Sector Promoters	11 states	Multiple HIEs	8 states
		One primary HIE	2 states
		No recognized HIE	1 state
Transitioning	3 states		