## **Impact of Health Disclosure Laws on Health Information Exchanges**

Idris Adjerid, Alessandro Acquisti, Rema Padman, Rahul Telang, Julia Adler-Milstein

## Preliminary Please do not distribute

Draft prepared for WEIS 2011

**Abstract.** Health information exchanges (HIEs) are expected to facilitate collaboration between healthcare entities and improve efficiency and quality of care through enhanced information sharing capabilities. Privacy concerns have been consistently cited as one of the primary challenges to HIE development and adoption. Currently, it is unclear how privacy laws – in particular, legislation restricting the disclosure of health records – have impacted the adoption of HIEs intended to facilitate sharing of health information. This study explores the landscape of health privacy legislation at the State level and examines the impact of variations in such privacy and confidentiality laws across the United States on the progress of HIEs.

#### 1. Introduction

In an effort to curb rising healthcare costs, recent legislative initiatives<sup>1</sup> have promoted the adoption of information technology in the healthcare sector. These initiatives created a variety of incentives for information technology adoption and health information sharing, including funding for states seeking to establish statewide Health Information Exchanges (HIEs). HIEs are information sharing collaborations between disparate health entities. They are expected to improve efficiency and quality of care through enhanced information sharing capabilities. However, the increased availability and digitization of health records via sharing raise concerns about the privacy and confidentiality of patients' sensitive information. Where does the balance lie between protecting health information and utilizing technology to improve efficiency and

<sup>&</sup>lt;sup>1</sup> The Health Information Technology for Economic and Clinical Health Act (HITECH) as part of the American Recovery and Reinvestment Act (Pub.L. 111-5).

quality of care? And what is the impact of privacy regulation on consumer welfare and firms innovation in the healthcare industry? Our current study is part of a stream of research that attempts to answer these questions. On one hand, strong privacy laws may hinder exchange of information. But on the other hand, strong laws may increase the confidence of the participants in the exchanges, which, in turn may signal success for HIEs. In this paper, we are interested in examining the impact of stronger privacy laws, limiting the disclosure of health information, on the pursuit and success of HIE efforts.

To answer this question, we contrast the adoption and success of Health Information Exchanges in states with laws that limit the disclosure of patient health information compared to states that do not have these laws. Our current results suggest a strong correlation between states with laws that limit the disclosure of health information and positive HIE outcomes. Moreover, we find that of all states with laws intended to promote HIE growth, only those that include requirements for patient consent see positive HIE outcomes. Interestingly, we also find that states with laws that introduce HIE disclosure restrictions without accompanying incentive see a strong negative impact on HIE outcomes. This points to some non-obvious benefits of such laws and suggests that it is some balanced appropriation of both carrot and substantive stick that works best to promote HIE growth and success.

Given the momentum HIE efforts have gained in the last several years, coupled with federal support for statewide HIEs, patient privacy has been a predominant concern for both the administrators of these efforts and federal and state regulators (Pritts et al, 2009). Studies such as ours can help inform this discussion and the attempts to balance improved health information sharing with patient privacy.

The next section provides background information on HIEs and the privacy issues surrounding these initiatives. Section 3 describes the extant literature on this topic, followed by an outline of our study hypotheses. The data used in this research is detailed in Section 5, the econometric models, analysis and results in Section 6, and discussions and conclusions in Section 7.

#### 2. Background

#### 2.1 Health Information Exchanges

Technology has been used to facilitate the flow of information between organizations in a wide variety of contexts. Many large scale-businesses use enterprise-wide systems to reduce costs and increase collaboration between previously isolated branches of their organizations (Shang & Seddon, 2000). The events of September 11, 2001 jumpstarted federal efforts to improve information sharing between isolated federal agencies to improve the nation's ability to react to potential threats to its security (Government Accountability Office, 2003). Similarly, the healthcare industry has attempted to facilitate the exchange of health information between segregated healthcare entities to capitalize on potential cost savings and increase quality of care for patients (eHealth Initiative, 2005). Effort to realize the potential gains from electronic health information sharing, often called Health Information Exchanges (HIEs), pursue the primary goal of facilitating sharing of health information between physicians, hospitals, health plans, pharmacies, laboratories, and other relevant entities.

HIEs have generally been regional partnerships of healthcare stakeholders that agree to share their patient health information and abide by some terms of use covering a wide range of issues such as subscription fees and patient privacy. Also, they often share some common technological platform for receiving and transmitting health information. Prior to recent history, successful HIEs have been few and far between with many early attempts hindered by sustainability challenges, misaligned incentives from competing healthcare entities, and technological and interoperability challenges. Despite the persistence of these challenges, the last five or six years have seen significant growth in HIE activity, including the number of HIEs attempted and an increasing number of HIEs actually sharing health information in a clinical context.

Although supporting empirical evidence is limited, HIEs have the potential to decrease the costs of healthcare. Jha et al (2009) estimate that, in the US, eliminating avoidable instances of injury to a patient resulting from a medical intervention, such as administering the wrong medication,

and redundant medical tests would save over 24 billion dollars in a single year. Walker et al (2005) estimate that, when fully implemented, HIEs could yield approximately \$ 78 billion dollars in annual savings. Broader gains in quality of care may also be realized due to the increased availability of comprehensive health information, which will allow clinicians to make better treatment decisions and fewer mistakes. This benefit would be especially salient in the emergency care context, in which the patient may not be able to report pre-existing conditions or drug allergies.

#### 2.2 HIEs and Privacy Concerns

Although HIEs promise a number of considerable gains, they have also elicited concerns from legislators, privacy advocates, and patient rights groups. One particular concern centers on the potential impact of the facilitated exchange of sensitive health information. On June 29, 2010, the American Civil Liberties Union filed suit against the state-sponsored exchange in Rhode Island, on grounds that it had not implemented sufficient controls to protect sensitive patient health information (Miliard, 2010). Additionally, experts have expressed the concern that HIEs will be a major source of future health privacy risk, citing failures to keep up with best practices and advancing technology, resulting in antiquated data security, governance, and policy (Bowman, 2011). These concerns have also been echoed by HIEs in self-reported surveys in which they consistently cite patient privacy concerns as significant challenges to HIE progress (eHealth Initiative, 2005-2010).

Specifically, some concerns focus on the risk that HIEs may lead to a loss of control of data by health providers, resulting in an increase in inappropriate use of sensitive patient health data (Bowman, 2011). From a security perspective, it is also widely accepted that, as the points of access to data increase, so do the points of attack. If careful consideration is not given to the security of HIEs, vulnerabilities in any system accessing the HIE may lead to exposure of sensitive health information. This concern may be significant when smaller providers (such as smaller physician offices) participate in a larger HIE, as the former may not have the resources and expertise to properly secure their local information systems. Additionally, as access to data increases, restricting inappropriate access and tracking access to health information become more

complex. One expert discussing HIE privacy and security concerns stated that, "To date, there have been no secure audit trails, ... if we can't track how and when private and personal information is accessed, we will never secure it" (Bowman, 2011). However, increasing HIE activity is not necessarily negative in terms of patient privacy. For example, a basic tenet of privacy protection involves providing patients access to their health information (OECD, 1980); in this regard, HIEs may actually facilitate patients' access to their health records across different providers and geographic areas.

One privacy issue that has generated significant discussion within the HIE community is the idea of soliciting patient consent to make their data available for exchange. State legislation in the area of health privacy often calls for solicitation of patient consent prior to the disclosure of health information. Many models have been proposed to obtain consent, including opting-in, opting-out, or not soliciting consent at all. Anecdotal evidence on the impact of various patient consent models on HIE success and adoption is mixed. There is some evidence that overly restrictive consent models have stifled the growth and information sharing capabilities of some HIEs (Pritts et al, 2009), while many other HIEs have successfully implemented methods of soliciting patient consent with relatively high rates of opt-in by patients (eHealth Initiative, 2007).

## 2.3 The Health Privacy Legislative Landscape

The privacy and security concerns associated with HIE are exacerbated by the complexities of the U.S. legal system (particularly across states), which leaves HIEs without a clear and consistent guidance for mitigating privacy risks. According to a recent report on consumer consent models for health information exchange, "the lack of uniformity (in state laws) is often viewed as one of the most complex challenges of implementing electronic exchange" (Pritts et al, 2009). The U.S. legislative landscape relative to health privacy can, indeed, be characterized as a patchwork of state and federal laws addressing various aspects of privacy concern.

In terms of federal law, sharing and use of health data is governed primarily by the Health Insurance Portability and Accountability Act (HIPAA) and associated regulation, which lay out requirements that address, amongst other things, patient consent, patient access to health records, use of de-identified health data, and security standards for health data. While HIPAA provides some protections for patients, it has been widely criticized by privacy advocates as being too lax to provide substantive privacy protections.<sup>2</sup> Most prominent in the complaints is the notion that HIPAA is defined too narrowly and does not provide adequate protection to patients from entities that generally handle sensitive patient data (such as information resellers, business associates, and researchers; however, recent federal amendments to HIPAA partially address some of these weaknesses).<sup>3</sup> Other federal regulations also provide some privacy protections with respect to patient health information. For example, the Confidentiality of Alcohol and Drug Abuse Patient Records Regulation (42 CFR Part 2) provides privacy protection for participants in federally funded substance abuse programs.

HIPAA is generally treated as a legislative floor for states upon which they are free to expand and further legislate to protect patient privacy. All states have either passed legislation in the wake of HIPAA or have not repealed pre-existing legislation dealing with health privacy concerns. It is important to note, however, that state laws may not necessarily provide protections that go above and beyond what is provided in HIPAA. In fact, many states refer to the HIPAA privacy protections either explicitly or implicitly when detailing state level protections.

State laws can be generally categorized under three main types: laws that (1) provide patients right to access, (2) restrict disclosure of patient information, and (3) define doctor patient privilege. These laws also apply in different ways to different health stakeholders in a state, such as physicians, hospitals, insurers, or HMOs, and may not apply to all healthcare entities that could participate in an HIE (e.g., a pharmacy). States may also have data-specific requirements, such as requirements only for health data on communicable diseases (such as HIV), substance abuse, or mental health. Together, these laws can determine a complex and inconsistent set of

<sup>&</sup>lt;sup>2</sup> Privacy Rights Clearinghouse, "HIPAA Basics: Medical Privacy in the Electronic Age" (2003). Center of Democracy and Technology, "Personal Health Records: Who Are You Going to Trust?" (2009). ACLU, "Coalition Letter on HIPAA Medical Privacy Regulations" (2001).

<sup>&</sup>lt;sup>3</sup> Ohara G.L. & Bernanke J.R., (2009), "ARRA's Amendments to HIPAA Privacy & Security Rules", Morgan Lewis.

requirements for HIEs to navigate. For example, it is not uncommon for a given state to have a law that requires consent prior to disclosure but only applies to hospitals and physicians, right to access legislation that only applies to HMOs and Insurers, HIV and mental health legislation that applies to all stakeholders, and doctor-patient privilege for psychiatrists only and not other physicians.

It is important to recognize that many of these laws were passed prior to the recent surge in HIE activity. While they still have applicability to HIEs, many were originally intended to deal with privacy concerns associated with paper records. As such, states have recently passed laws specific to HIEs that often specify requirements relating to patient privacy, including patient consent and data security.

Other recent trends in state legislative action with direct applicability to HIE include the passing of data breach notification laws. These may be especially relevant with some experts predicting that HIE growth will result in an increase in fines and regulatory actions due to increased breaches and cost increases due to a rise in penalties. Lastly, Health IT legislation may impact HIE activities. For example, in 2009 New Mexico passed the Electronic Medical Records Act, which included, amongst other things, patient privacy protections specific to HIEs.

In summary, HIEs are faced with the arduous task of evaluating and balancing a patchwork of state legislation that form a complicated web of requirements, spanning hundreds of statutes and covering a wide range of stakeholders and data types. We exploit this complexity to contrast the adoption and success of Health Information Exchanges across states with differing health disclosure protections. Using both cross sectional and time fixed effect analyses, we investigate whether states with stronger privacy laws, limiting the disclosure of health information, were more or less likely to pursue HIE efforts and had more HIEs exchanging data.

#### 3. Related Work

A few recent studies have examined issues relating to Health Information Exchange, privacy in the context of sensitive health data, and the intersection of privacy and health technology adoption.

A significant body of work has looked at patient and physician attitudes towards privacy in the context of person health information. Sankar et al (2003) find that patients felt strongly that only those involved in their care should have access to their information but also identified with the need of physicians to share their health information. They also found that patients dealing with increasingly sensitive information (HIV for example) are less likely to share their information. Ness (2007) reports that a 68% of epidemiologist researchers felt that HIPAA made research more difficult, while only 25% felt that it increased patient privacy. Specific to HIE, Simon et al (2009) perform a qualitative study of patients attitudes towards HIE and found that privacy, security, and consent issues consistently came up as concerns (although attitudes towards importance of these protections varied). They also found that with the information provided them by the research (regarding both HIE benefits and privacy/security protections) 88% stated that they would consent to inclusion of their personal health information. Furthermore, Wright et al (2009) analyze 1043 physician responses to a survey on HIE, in which 16% reported being very concerned about HIE's effect on privacy, while 55.0% were somewhat concerned and 29% not at all concerned.

Specific to the intersection of HIE and privacy, Goldstein & Rein (2010) explore consumer consent options in the context of health information exchange, detailing the evolution of various consent models and the impact of state and federal legislation on the development of these models. More broadly, Angst (2009) discusses some of the questions revolving around the balancing of patient privacy and the substantial benefits promised by health information exchange. He argues that some of these trade offs can be partially mitigated through technological innovation (such as designing systems that allow granular consent), and also advocates increased education of the public on the benefits and risks of health information exchange. McGraw et al (2009) echo this sentiment arguing that a comprehensive framework

that implements core privacy principles, adopts trusted network design characteristics, and establishes oversight and accountability mechanisms can bolster trust and promote adoption.

Experts also present somewhat conflicting views on the current legislative environment and its applicability to the HIE landscape. Greenberg et al (2009) argues that the HIPAA and state privacy protections are dated and need to be revisited in light of the emergence of a National Health Information Network (which is envisioned to ultimately link regional and state-level HIEs). Mcdonald (2009) adds that while additional protections may be warranted in the context of a national exchange, at the local level restrictions that go beyond HIPAA would interfere with efficient and safe care.

Finally, previous work closely related to our investigation looks into the impact of legislation and regulation on healthcare costs and technology adoption. Miller & Tucker (2009) examine the impact of health disclosure laws on EMR adoption and find that disclosure laws inhibited positive externalities resulting in a 24% reduction in EMR adoption. Shen et al (2006) argues that complexities relating to patient consent are time-consuming and increase costs.

#### 4. Hypotheses

Our goal is to determine the impact of stronger privacy laws, limiting the disclosure of health information, on the pursuit of HIE efforts and whether HIEs reach operational status or fail. The role of privacy protections in the adoption of technology efforts to facilitate sharing of health information is currently ambiguous.

On the one hand, increasingly stringent restrictions on the disclosure of health information could inhibit the success of exchange efforts through increased cost associated with the sharing of health information. These may be direct costs to the HIE in the form of increased investment in privacy and security protective technologies or staff specializing in privacy and security issues. Costs on HIEs from stringent restrictions could also materialize in the form of increased liability to the exchange participants (providers, hospitals, etc.). In some states, inappropriate disclosure of sensitive health information is treated as a criminal offense and other states provide legal avenues to seek damages based on inappropriate disclosure of sensitive health information. These liabilities become even more severe in the context of highly sensitive health information such as HIV or mental health data.

Furthermore, laws that deal with the disclosure of health data generally require that providers solicit consent from patients prior to disclosing their personal information. Garnering consent from patients adds administrative burdens to HIEs and could also lead to increased costs from efforts to communicate and educate patients on the benefits and risks of HIE. Patient consent may also reduce the functionality and utility provided by an HIE, as patients may consent to only partial or incomplete inclusion of their health data. For instance, a patient may agree to include their general health information but not information about their mental health or communicable diseases they may have, which could lead to misdiagnoses by providers and treatment decisions harmful to the patient.

On the other hand, it is possible that increased privacy protections could facilitate HIE progress and success. As we noted previously, HIEs have drawn considerable scrutiny from patient rights groups, privacy advocates, and regulatory bodies on patient privacy grounds. Consequently, stronger privacy protections could mediate some of these concerns thus encouraging HIE growth and success. Given that health data privacy sensitivities exist even in states with weaker legislative protections, state with more prescriptive legislation dealing with privacy may result in a less ambiguous operating environment for HIEs. Restrictive legislative environments may in effect force the "privacy issue," resulting in HIEs that are foresighted in terms of handling privacy concerns, engaging the local community, and developing mitigating technology and policies. This increased attention to privacy and increased foresight may help HIEs to avoid expensive and time consuming retrofitting and other roadblocks in the future as a result of patient privacy concerns.

Lastly, it is also likely that a number of different effects- both positive and negative - are operating simultaneously, in which case the question becomes: what is the net effect of increasingly stringent privacy protections on HIE adoption and progress? Given the significant role HIEs are likely to play in the revitalization and streamlining of the ailing U.S. healthcare

system, insights into this question will be helpful in balancing patients' right to privacy and facilitated sharing of patient health information.

## 5. Data

In order to determining the impact of privacy laws on HIE efforts and success, we contrasted the adoption and success of Health Information Exchanges in states during the period of 2004-2009 (this is when HIE gained significant traction in the US) with laws that limit the disclosure of patient health information compared to states that do not have these laws. Our initial analysis found that HIE disclosure restrictions are governed primarily by two broad categories of state laws:

- Health Disclosure Laws: Laws that govern the disclosure of general health information absent the specific context of HIE. While they have applicability to HIEs, these laws generally predate significant HIE activities.
- HIE Specific Laws: Laws passed relating to various aspects of HIE development and often also specify requirements relating to patient privacy and security.

To identify states with *health disclosure laws*, we relied on both the recent compilation of state disclosure laws by Pritts et al (2009) and the earlier compilation of general state privacy laws by Pritts et al (2002). Through these resources, we identified states with laws that require healthcare entities to garner authorization from patients prior to disclosing general patient health information. States have also legislated additional requirements for disclosure of highly sensitive patient information (mental health, HIV, etc.), which for the sake of manageability are not within the scope of this work. There are other types of laws that also relate to the protection of patient privacy (right to access, patient doctor privilege, etc.), which are less relevant to HIE efforts and not included in our analysis.

Because HIEs are likely to include a broad range of healthcare entities, we used a relatively stringent standard to designate a state as having a *health disclosure law*. States had to have laws that (at a minimum) limited disclosure by physicians, hospitals, Health Maintenance Organizations, and insurers. We did not differentiate states based on secondary details of the

various laws (i.e. looking at exceptions to soliciting consent from patients or whether their protections go beyond HIPAA requirements).

We also used the annual Privacy Journal's Compilation of State Privacy Laws (Smithe & Ryder, 2002) (updated to 2010) and individual online legal references from each state to validate the continued existence of these laws, update any changes to these laws, and identify new laws that had been passed. We identified 21 states with laws that met our requirements for have a health disclosure law. For our time period of interest (2004-2009), general health disclosure laws were relatively unchanged and were used in our cross-sectional analysis.

Figure 1: States with Health Disclosure Law (2009)



🔶 - With Disclosure Law

Because of the lack of significant variation in general health disclosure legislation during the time period of our data, we focused on more recent HIE-related legislation in our time-series analysis. We identified these laws primarily through various legal search services (e.g. LexisNexis academic and Westlaw) and supplemented these searches with recent reports on disclosure laws and Health Information Exchange (Goldstein & Rein, 2010). We categorize

states into one of four mutually exclusive categories (See Appendix A for some examples of these legislative actions):

- ProHIE Only States with laws intended to promote HIE (such as creating an exchange, providing funding for HIE activities, or designating a government entity to facilitate health information exchange) but make no mention of patient privacy considerations in the context of exchange. (4 states)
- ProHIE and Consent: States with laws intended to promote HIE and also explicitly require HIEs to solicit patient consent. (7 states)
- ProHIE Law and No Consent: States with laws intended to promote HIE, make some mention of privacy protections but do not require HIEs to solicit patient consent. (11 states)
- HIE Privacy Only: These are states that don't have legislation to encourage HIE growth but have relevant privacy legislation citing HIEs or information exchange. (3 States)



## Figure 2: States with HIE-Specific Laws

#### 5.1. Health Information Exchanges

For this study, we defined an HIE as any project or initiative focused around electronic health data exchange between two or more disparate organizations or stakeholders. To identify a comprehensive set of HIEs, we started from publicly available data from the eHealth Initiative's (eHI) annual compilation of state, regional, and local HIE efforts (eHealth Initiative, 2005-2010). Additionally, we validated and condensed their list through online research and communications with HIE representatives. Lastly, we consolidated our data set with data from a national survey of Health Information Exchanges [17] to further validate our dataset. Through this process, we identified 312 HIE initiatives. At the end of 2009, 88 of these initiatives were operational and actively exchanging health information, 132 initiatives were still planning to become operational, and 92 had failed. At the end of 2009 there were 220 HIEs (Planning + Operational) still pursuing exchange effort. Of these efforts, we had 165 survey responses that provided additional information on specific HIE characteristics (e.g. reliance on federal funding, number of patients covered, type of data being shared, when they started pursuing HIE efforts, and when they became operational).

A general overview of the distribution of operational HIEs across states is given in Figure 2 below:

#### Figure 2: Number of Operational HIEs by State

- 🔶 One
- 🔶 Between Two and Four
- 🔶 Five or More



Figure 2 suggests that states with HIE activity seem to generally be the same states that have health disclosure laws (Figure 1). We present this only as an observation of correlation, acknowledging that the states identified in Figure 2 are likely correlated along other important dimensions as well (e.g. state population or resident wealth). Our data also demonstrates an uneven advancement of HIE efforts with nearly half of states having none to very little HIE activity. Also, we see some clustering of operational HIEs with 30% of operational HIEs contained within three states (New York, California, and Florida).

Building on this observational relationship, we examine the impact of the specific disclosure laws of interest described earlier on the success and failure of HIEs using econometric models.

#### 6. Analysis

#### 6.1 Cross-Sectional Analysis

We first present the results of a cross-sectional analysis using an aggregated dataset summing up all HIE activity during our time period (2004-2009). This data set gives a fairly complete picture of where each state had reached in terms of HIE by the end of 2009.

We initially used a cross-sectional approach for two reasons: 1) To explore initial correlations between health disclosure laws and HIE outcomes; and 2) our time-series data is incomplete or lacking for some data measures. For example, we do not have reliable or complete data on when exactly HIEs failed during the time-span of our data, but we know that they been initiated and had subsequently failed prior to the end of 2009.

Through an analysis of some of the more impactful work in the HIE area, we identified a number of variables of interest with respect to HIE progress and success. One such work is the annual eHi survey, which looks closely at, amongst other things, how many HIEs are being attempted (Total HIE) and how many have crossed the threshold into sharing health information (Operational HIE). We further explore this aspect of HIEs sharing health information by also evaluating the length of time it takes an initiative to reach that status. Moreover, other studies, such as Adler-Milstein et al (2008), found that HIEs have had a notably high failure rate, with many initiatives failing to build sustainable business model and properly solicit community buyin. We attempt to capture the volatility in the HIE domain through our measure of failed HIEs. All of the measures we use in this analysis are summarized in Table 1.

Measure	Description
Total HIE	The total number of attempted HIEs
Operational HIE	The total number of HIEs actively exchanging data
Failed HIEs	The total number of failed HIEs
Operational Rate	Total operational HIEs relative to the total attempted
Failure Rate	Total failed HIEs relative to the total attempted

Table 1: Measures of Interest with Respect to HIE Progress

For our analysis, we use general health disclosure laws as the independent variable of interest (summarized in Figure 1), because of their direct applicability to the sharing of health information, and because they have almost exclusively been passed prior to the substantial growth to HIE. As such, we are confident that these laws have applicability to HIE activities, but are less concerned about the endogenous passing of these laws as a reaction to HIE growth and progress.

We start by exploring the effect of health disclosure laws by looking at the number of Operational and Attempted HIEs in a state (Table 2a).

Measure	Law	No Law	P-Val
Total HIE***	9	4.1	0.0010
Operational HIE***	3.095238	.8	0.0002
Failed HIE*	2.333333	1.43333	0.0638

Table 2a: Total, Operational, and Failed HIEs by Health Disclosure Law

We see that states with these disclosure laws have more than twice as many HIEs attempted and close to 4 times as many HIEs that are operational. However, we do find that states with these health disclosure laws had more failed HIEs (although a weakly significant difference). We suspect that, as these are raw counts, we are picking up some strong scale effects. That is, states

with disclosure laws also have larger populations, which may be driving some of the differences we see initially. Results normalized by population are presented in Table 2b.

 Table 2b: Total, Operational, and Failed HIEs by Health Disclosure Law (Normalized by Population)

Measure	Law	No Law	P-Val
Total HIE	14.05101	14.54214	0.4432
Operational HIE**	5.252693	2.494582	0.0199
Failed HIE**	2.414936	5.830914	0.0434

Table 2b confirms some of our suspicions: the difference between states in terms of the total number of HIEs fades away when scale effects are accounted for. However, states with health disclosure laws still exhibit more operational HIEs; this effect is robust to inclusions of scale effects. Most interestingly, we see that when we account for scale effects, we find the opposite effect on failed HIEs. That is states with health disclosure laws had in effect less failed HIEs (p < .05).

We continue our analysis comparing the operational and failure rates of states relative to health disclosure laws (Table 2c).

Table 20. Time to Operation and Operational and Fanure Rates by Health Disclosure Law					
Measure	Law	No Law	P-Val		
Operational Rate***	.356678	.1721627	0.0075		
Failure Rate*	.2265268	.3590013	0.0557		

 Table 2c: Time to Operation and Operational and Failure Rates by Health Disclosure Law

Table 2c shows a positive correlation between health disclosure laws and HIE progress, with states with these laws having high rates of operational HIEs and lower rates of failed HIEs.

## 6.2 Econometric Model

A simple econometric model is used to further explore the correlation between HIEs activities and health disclosure laws and control for the strong scale effects on the aggregate counts of HIE activity. We also control for a series of factors highlighted by our preliminary analysis: states with health disclosure laws are generally coastal states with higher population, tend to be wealthier states, share a common political orientation, and exhibit higher level of technological sophistication (measured level of broadband access in a state). Other potential covariates included various categories of state GDP (e.g. health sector and computer services) and the measures of state legislative professionalism proposed by Squire (2003). However, for the sake of parsimony, we only included population to capture these effects, as we found that these covariates were highly correlated with population. Lastly, we included controls for HIE-specific legislation, which is also likely impacting HIE growth and success. The resulting model is presented below:

## Econometric Model 1: Basic Cross Sectional Analysis

 $DependentVariables_{state} = \beta o + \beta 1^{*}HealthDisclosureLaw_{state} + \beta 2^{*}Population_{state} + \beta 3^{*}PopulationSquared_{state} + \beta 4^{*}BroadbandAccess_{state} + \beta 5^{*}Blue_{state} + \beta 6^{*}PerCapitaGDP_{state} + \Sigma \delta_{i}^{*}HIELaw + \mu$ 

Because our dependent variables are generally counts, we used a Poisson regression to estimate our model. The Poisson regression model provides a relatively robust analytical framework and is effective at estimating a range of dependent variables. In table 3a, we estimate Model 1, using standard approaches with our raw counts columns **1**,**3**, and **5** and normalized counts in **2**,**4**,**6**. All of our results are all reported using robust standard errors.

	Total HIE		Operati	<b>Operational HIE</b>		Failed HIE	
	(1)	(2)	(3)	(4)	(5)	(6)	
	Standard	Normalized	Standard	Normalized	Standard	Normalized	
Disclosure	0.031	0.245	0.654	1.114 (3.04)***	-0.513	-0.977 (2.85)***	
	(0.19)	(1.23)	(2.03)	(3.04)	(1.95)	(2.83)	
Population	0.161 (8.44)***	-0.099 (3.15)***	0.158 (4.49)***	-0.115 (1.72)*	0.157 (6.08)***	-0.063 (1.27)	
Population Squared	-0.003 (6.68)***	0.002 (2.35)**	-0.003 (3.37)***	0.002 (1.29)	-0.002 (3.42)***	0.002 (1.53)	
Democratic State	0.269 (1.64)*	-0.135 (0.67)	0.340 (1.15)	0.519 (1.38)	0.135 (0.55)	-0.245 (0.68)	
Broadband Access	-0.002 (0.23)	0.008 (0.68)	-0.011 (0.46)	-0.024 (0.87)	0.018 (0.95)	0.063 (2.94)***	

Table 3a: Evaluation of Total HIEs, Operational HIEs, and Failed HIEs counts

Per Capita	0.009	0.016	0.007	0.025	0.005	0.004
GDP	(2.08)**	(7.33)***	(0.82)	(3.06)***	(1.06)	(0.87)
ProHIE and	0.077	0.331	0.203	-0.270	0.270	0.740
Consent	(0.67)	(1.37)	(0.69)	(0.58)	(1.18)	(2.00)**
ProHIE and	0.009	-0.035	0.020	0.045	-0.118	-0.212
No Consent	(0.06)	(0.21)	(0.06)	(0.14)	(0.52)	(0.61)
<b>ProHIE Only</b>	-0.686	-0.299	-0.360	-0.624	-0.387	0.503
	(3.75)***	(1.53)	(0.96)	(0.90)	(1.37)	(0.98)
Privacy Only	-0.596	-0.195	-0.291	-0.021	-1.130	-0.683
	(3.61)***	(0.96)	(0.40)	(0.03)	(1.31)	(0.68)
Observations	51	51	51	51	51	51
* significant at	10%; ** signi	ficant at 5%; **	** significant a	at 1%		

Our results in Table 3a generally confirm what we find in our summary analysis. We confirm our initial results showing positive but generally insignificant correlation in columns **1** and **2** on *Disclosure Law* for Total HIEs attempted. We also confirm the result we found for operational HIEs with a positive and significant coefficient on *Disclosure Law* in columns **3** and **4**. Also, the magnitude of the effect here is sizable showing that states with disclosure have as much as twice times as many operational HIEs. Lastly, we see a strong negative coefficient in column **5** and **6** on *Disclosure Law* for failed HIEs.

To further explore the correlation between HIE progress and health disclosure laws, we estimate our model for operational and failure rates of HIEs in Table 3b below:

 Table 3b: Evaluation of Operational and Failure Rate

	Operational Rate	Failure Rate
	(1)	(2)
Disclosure Law	0.722 (2.03)**	-0.533 (1.74)*
Population	-0.015 (0.27)	0.005 (0.11)
Population Squared	0.000 (0.19)	0.000 (0.35)

Democratic State	0.384	-0.220			
	(0.98)	(0.66)			
Broadband Access	-0.021	0.030			
	(0.80)	(1.45)			
Per Capita GDP	0.009	-0.006			
	(0.86)	(0.95)			
ProHIE and Consent	-0.281	-0.035			
	(0.80)	(0.11)			
ProHIE and No Consent	0.247	-0.213			
	(0.78)	(0.78)			
ProHIE Only	-0.421	0.380			
	(0.51)	(0.78)			
Privacy Only	0.167	-0.503			
	(0.23)	(0.56)			
Constant	-1.232	-2.168			
	(1.09)	(2.28)**			
* significant at 10%; ** significant at 5%; *** significant at 1%					

Again, we see confirmation of our initial analysis, with the coefficient on *Disclosure Law* positive and significant in column **1**. Similarly, we see a negative and significant coefficient on *Disclosure Law* for Failed HIEs in column **2**. We can interpret these coefficients as percent changes in the operational and failure rates. Consistently, we observe a positive correlation between health disclosure laws on HIE progress across a number of HIE outcomes, indicating that there may exist some subtle beneficial impacts of health disclosure laws.

However, our cross-sectional analysis does not provide an estimate of the causal effect of health disclosure laws. This is largely due to potential bias from both relevant omitted variables and endogeneity in the form of unobservable in our error term that are correlated with both a state's likelihood to pass these laws and also have successful HIE efforts. For example, general attitudes and motivations towards the advancement of the healthcare field are likely to vary across states. It is also possible that these attitudes are also correlated with health privacy sensitivities, driving the observed correlation between HIE success and health disclosure laws. These concerns are even more salient given that our data is at the state level, introducing arguably innumerable

dimensions across which states vary that could also interact with health privacy sensitivities to bias our results.

With cross-sectional analysis, instrumental variables (IV) can be useful in identifying casual effects. We utilize this approach building on some IVs used in prior work and generally find directionally consistent results (See Appendix B). We don't lean heavily on our IV analysis for identifying casual effects due to the stringent requirements associated with IV analysis, and the subsequent difficulty in identifying IVs that adequately meet these requirements.

#### 6.3 Panel Analysis

To complement our cross-sectional analysis and address some of the limitations of IV analysis, we looked at some recently passed HIE-specific legislation. These laws enrich our analysis across a few key dimensions. Firstly, one may argue that general health disclosure laws are somewhat dated and were passed prior to the prominence of HIEs (although there is evidence that state health disclosure laws have shaped the consent and privacy culture for HIEs) and are thus less relevant to HIE activities. These laws, on the other hand, were passed specifically with HIEs in mind and have direct applicability to HIEs and their activities. Additionally, these laws were passed in the last 5 to 6 years, allowing us to run time-series analysis over our dataset and gain some insight into the casual effect of various laws. Lastly, these laws introduced some interesting variability across states - with states ranging from no HIE-specific legislation to legislation imposing stringent disclosure requirements for HIEs.

While the recent enactment of these laws provides some advantages, it also raises one immediate concern: these laws may not be driving HIE activity, but indeed are passed as a result of increased HIE activity. In order to address this concern, we plot operational HIEs for states that pass these HIE laws against those that don't. Figure 3 below shows that in the period prior to the passage of these laws (2004-2006), there are small differences between the states that pass these laws and states that don't. However, as we move into 2007 (most of HIE laws we identified were passed around this time frame) we see a growing difference between states with and without HIE

laws, suggesting some effect of these laws (although the differences are still slight and are not significant in any year).



Figure 3: Trend of Operational HIEs relative to HIE Laws

As we noted above, we categorize HIE laws into one of four categories: (1) ProHIE and Consent, (2) ProHIE and No Consent, (3) ProHIE, and (4) Privacy Only. Figure 4 below examines how these various categories of HIE laws are related to operational HIEs.

Figure 4: Trend of Operational HIEs relative to Specific HIE Law Type



From Figure 4, we notice that states that pass HIE promoting legislation with no consent requirements seem to have initially more activity but maintain a similar trajectory of growth even after the passing of these laws. Also, we see that states with legislation both promoting HIE growth and also providing for patient consent seem to display a sharp increase in HIE activity around the passage of these laws (on average these laws were passed in 2007). Lastly, we see little HIE growth for states with HIE only and Privacy Only legislation. However, this is a relatively rare occurrence with 3 and 4 states (respectively) with this designation.

We now specify an econometric model to evaluate the impact of the laws' adoption on the number of Operational HIEs and Total HIEs attempted. This subset of the dependent variables used in our prior analysis was chosen because we had sufficiently complete longitudinal data on them for the HIEs in our dataset. For our TotalHIE measure, we did not have sufficient longitudinal data on failed HIE initiatives, thus we only included the HIEs available to take our survey at the end of 2009. This alters the interpretation of this dependent variable slightly relative to our cross-sectional analysis. In the context of our panel analysis, TotalHIE is capturing the resilient HIE entrants (those that haven't failed as of 2009). The HIEs that have been founded in recent years confound this interpretation, as they will show up in our counts but their resilience is yet to be seen. This confound is relatively minor given that we only identify 18 of our 152 HIEs that are less than one year old and these young HIEs are roughly evenly distributed between states with and without HIE laws (40% and 60% respectively). We do not have these concerns for our longitudinal measure of OperationalHIEs because in our time period, no HIEs because operational then subsequently failed. We have semiannual data for our laws of interest and HIE variables from 2004-2009. We specify the following model:

#### Econometric Model 2: Basic Fixed Effects Model

 $TotalHIE_{st} & Operational HIE_{st} = \beta o + \Sigma \beta_i * HIELaw_{st} + \Sigma \alpha_i HIELaw_{st} * HealthDisclosureLaws_s + \theta_s + \lambda_t + \mu_{st}$ 

HIELaw<sub>st</sub> is a dummy variable, coded as 1 (one) if the state has adopted the law and zero otherwise. Because we have categorized our HIE laws into several categories of interest we include them all in our analysis with the left out category being "No HIE Law". The dates of

adoption and content of HIE laws were obtained from searches on various legislative search engines (Westlaw and LexisNexis Academic) and state legislature websites. We also include terms to evaluate the interaction between the HIE laws and health disclosure laws.  $\theta_s$  and  $\lambda_t$  are state and time fixed-effects and  $\mu_{st}$  is the familiar error term. This state, time fixed effect model has been used in the literature to examine the effect of a policy intervention (Bertrand et al., 2004). State fixed effects allow us to control for unobserved state specific factors and time dummies allow us to control for time trends. Thus, the unbiased effect of HIELaw can be identified from variation across state and time.

Because HIE laws have generally been passed primarily to encourage HIE growth in states (22 of the 25 HIE laws we identified are primarily intended to promote HIE growth), we need to extend our model in order to better identify the effect of the privacy protections specified in these laws. More simply, we need to ensure that any effect we see is not just effects of other major provision of the HIE law. For this reason, we also control for provisions in HIE laws that encourage HIE growth such as providing HIE funding and designating a state sponsored HIE. Additionally, we include population as a control to account for the scale effects we see in our prior analyses. The resulting specification is describe in Model 5 below and estimates of this model are provided in Table 4.

#### Econometric Model 3: Full Fixed Effects Model

 $TotalHIE_{st} & Operational HIE_{st} = \beta o + \Sigma \beta_i * HIELaw_{st} + \Sigma \alpha_i HIELaw_{st} * HealthDisclosureLaws_s + \delta_1 * Funding + \delta_2 * StateDesignatedHIE + \delta_3 * Population + \delta_4 * PopulationSquared + \theta_s + \lambda_t + \mu_{st}$ 

In Table 4 BELOW, we observe sizable and positive coefficients on *ProHIE and Consent* for both Total HIE and Operational HIEs. The coefficient for Total HIE is significant (P < .05) and the coefficient on operational HIEs is weakly significant, suggesting a positive impact of this type of legislative environment on HIE activity. Additionally, when we include the interaction terms of *HIELaw* with *HealthDisclosureLaw*, we observe that the positive effect of "ProHIE and Consent" is driven strongly by the states that also had prior health disclosure laws (P<.01). Also, we see a negative and weakly significant coefficient on "Privacy Only" legislation, indicating a negative impact of privacy requirements without matching HIE incentives. Lastly, we see insignificant coefficients on "ProHIE with No Consent" and "ProHIE only" suggesting that promoting HIE without substantive privacy protections was not effective in encouraging HIE growth. While not the focus of our analysis, we also note that legislation identifying a statedesignated HIE had a stifling effect on HIEs attempted with a strong negative impact on the number of HIEs attempted.

	Tota	IHIE	<b>Operational HIE</b>		
	(1)	(2)	(3)	(4)	
ProHIE and	2 151	-0.063	0 692	-0 370	
Consent	(2.28)**	(0.16)	(1.69)*	(1.32)	
<b>ProHIE and No</b>	-0.047	-0.189	0.021	-0.281	
Consent	(0.14)	(0.51)	(0.07)	(0.62)	
<b>ProHIE Only</b>	-0.224	-0.182	-0.122	-0.086	
	(0.54)	(0.45)	(0.35)	(0.26)	
Privacy Only	-2.791	-1.091	-1.131	-0.743	
	(1.94)*	(2.82)***	(1.95)*	(4.33)***	
StateDesignated	-1.974	-1.758	-0.197	-0.113	
	(2.59)**	(3.09)***	(0.51)	(0.29)	
Funding	-0.300	-0.335	-0.211	-0.276	
	(0.73)	(0.85)	(0.57)	(0.87)	
Population	-1.851	-1.775	-1.751	-1.758	
	(1.83)*	(1.91)*	(1.59)	(1.66)	
Population	0.00006	.00006	0.00003	.00007	
Squared	(2.01)**	(2.14)**	(1.63)	(1.74)*	
ProHIE &		2.309		1.276	
<b>Consent * Health</b>		(3.46)***		(3.03)***	
Disclosure Law					
ProHIE & No		0.293		0.592	
Consent * Health		(0.56)		(1.17)	
Disclosure Law					
Privacy Only *		-3.504		-0.685	
Health		(1.52)		(0.65)	
Disclosure Law			1.510	1.505	
Constant	3.303	3.282	1.512	1.527	
	(6.37)***	(6./1)***	(3.45)***	(3.54)***	
Time Fixed	YES	YES	YES	YES	
Effects	VEQ	VEQ	VEO	VEC	
State Fixed	YES	YES	Y ES	YES	
Charmationa	(12	(12	(12	(12	
Number of ID	51	51	51	51	
D squared	0.40	0.52	0.41		
<b>n-squared</b>	U.47	U.32	0.41 t the 1%	0.43	

 Table 4: Panel Analysis of HIE Legislation and HIE Activity

Figure 5 below presents a between state comparison evaluating the differences between different HIE regulatory regimes, using "Pro HIE and Consent" states as our base category of comparison. When compared with "Pro HIE and No Consent", we find that states with Pro HIE legislation and strong privacy had more successful HIE entrants (P < .05), but did not have a significant difference for Operational HIEs. We also find that "Pro HIE and Consent" states have more successful HIE entrants and more operational HIEs than both "ProHIE only" and "Privacy Only" states.





#### 7. Discussion and Conclusions

This study evaluates the impact of health disclosure laws on HIE progress and success. We use a range of econometric approaches commonly used in the literature and have controlled for various limitations in the data. Although our results are preliminary with investigations of possible endogeneity still in-progress, we identify a strong correlation between states with laws that limit the disclosure of health information and positive HIE outcomes. Moreover, we find that of all states with laws intended to promote HIE growth, only those that include requirements for patient consent see positive HIE outcomes. Interestingly, we also find that states with laws that

introduce HIE disclosure restrictions without accompanying incentive see a strong negative impact on HIE outcomes.

The results of this paper may be of interest for a variety of reasons. Firstly, our study may inform current and future efforts to incentivize HIE growth, and other similar technologies that promise some public benefits but are inherently privacy sensitive. More specifically, it suggests that weak and lacking privacy protections in the context of privacy sensitive technologies may dampen the effectiveness of incentives for adoption.

These results do not contradict previous work suggesting that health disclosure laws have had a negative impact on EMR adoption. For example, the inhibiting effect of privacy protections without accompanying incentives may be reflective of the time-period in which prior work evaluated the role of health disclosure laws. Moreover, the dynamics that impact the pursuit and success of HIEs may be quite different from the adoption of electronic medical records, and as such may have dissimilar interactions with health disclosure laws

The various dependent variables presented in this work do not cover the full breadth of potential measures of success for HIEs. Most obviously, we would be interested in evaluating more substantive aspects of HIE sharing rather than just whether they are sharing or not. While we believe that reaching operational status is a significant milestone for HIEs, work in the realm of HIEs area has also noted that sharing by HIEs has been limited in breadth and scope. Exploring the effects of these laws on how much HIEs are sharing what type of data is being shared would bee a natural and relevant extension of this work.

Lastly, we caution the reader against drawing the incorrect conclusion from this work that all of the laws we grouped together and used in this study were perfectly uniform. It was a necessary simplification for this work that we use manageable criteria for categorizing laws related to health information disclosure and HIE. In reality, some of these laws may be complex with various nuances that may make some laws more or less effective than others. The results presented in this manuscript have implications for policy makers at both the state and federal level. Often, technological progress and privacy protection sit on opposite ends of the table negotiating terms seeking to balance the two. These concerns may be increasingly salient in the case of HIEs given their direct privacy implications, and the considerable attention that has been given to various privacy and security concerns. The results in this paper suggest that at least in the context of HIEs, stronger protections seem to go together with incentives for the development and success of these efforts. More generally, our paper provides some evidence that it may be a balanced combination of carrot and substantive stick that works most effectively to promote privacy-sensitive technologies.

## 8. References

- 1. Adler-Milstein J., McAfee A.P., Bates D.W., Jha A.K., (2008), "The State Of Regional Health Information Organizations: Current Activities And Financing", Health Affairs, 27:1, w60-w69.
- 2. Adler-Milstein J., Bates D.W., Jha A.K., (2009), "U.S. Regional Health Information Organizations: Progress but Challenges Remain", Health Affairs, 28:2, 483-492.
- 3. Angrist J. D., (2001), "Estimation of limited dependent variable models with dummy endogenous regressors: Simple strategies for empirical practice", Journal of Business and Economics Statistics, 19:2-16.
- 4. Angst C.M., (2009), "Protect My Privacy or Support the Common-Good? Ethical Questions About Electronic Health Information Exchanges", Journal of Business Ethics, 90:169–178.
- 5. Angst C.M., Agrawal, R. and Downing, J., (2006), "An Empirical Examination of the Importance of Defining the PHR for Research and for Practice", http://ssrn.com/abstract=904611.
- 6. Annas G.J., (2003), "HIPAA Regulations A New Era of Medical-Record Privacy?", New England Journal of Medicine; 348:1486-1490.
- 7. Appari A., Johnson E.M., (2010), "Information security and privacy in healthcare: current state of research", International Journal of Internet and Enterprise Management, 6:4, 279–314.
- 8. Arendt J.N., Holm A., (2006), "Probit Models with Binary Endogenous Regressors", Centre for Applied Microeconometrics, Department of Economics University of Copenhagen.

- 9. Bansal G., Zaheid F.M. Gefen D., (2007), "The impact of personal dispositions on privacy and trust in disclosing health information online", Americas Conference on Information Systems, Keystone, CO, http://aisel.aisnet.org/amcis2007/57.
- 10. Baumer D.L., Earp, J.B. and Payton, F.C., (2000), "Privacy of medical records: IT implications of HIPAA", ACM Computers and Society, 30:4, 40–47.
- 11. Bertrand M., Duflo E., Mullainathan S., (2004), "How Much Should We Trust Differences-in-Differences Estimates?" Quarterly Journal of Economics, 119:1, 249-275.
- 12. Bowman D., (2011), "Panel: HIEs will be a major privacy concern in 2011", Jan 6 2011 11:11am, FierceEMR.com, http://www.fierceemr.com/story/panel-hies-will-be-major-area-privacy-concern-2011/2011-01-06.
- Boyens C., Krishnan R., Padman R., (2004), "On Privacy-Preserving Access to Distributed Heterogeneous Healthcare Information", Proceedings of the Proceedings of the 37th Annual Hawaii International Conference on System Sciences (HICSS'04) - Track 6, p.60135.1, January 05-08.
- 14. Brailer D. J., (2005), "Interoperability: The key to the future health care system," Health Affairs, w5-w19.
- 15. Breaux T., Antó A.I. (2007), "Analyzing Regulatory Rules for Privacy and Security Requirements". North Carolina State University Technical Report TR-2007-9.
- 16. eHealth Initiative, (2005), "Emerging Trends and Issues in Health Information Exchange", http://www.ehealthinitiative.org/sites/default/files/file/eHI2005AnnualSurveyofHealthInformatio nExchange2\_0.pdf.
- 17. eHealth Initiative, (2006), "Improving the Quality of Healthcare through Health Information Exchange", http://www.ehealthinitiative.org/files/eHI2006HIESurveyReportFinal09.25.06.pdf
- 18. eHealth Initiative, (2007), "Fourth Annual Survey of Health Information Exchange At the State and Local Levels", http://www.ehealthinitiative.org/sites/default/files/file/2007 HIE Survey results.pdf
- 19. eHealth Initiative, (2008), "Fifth Annual Survey of Health Information Exchange At the State and Local Levels", http://www.ehealthinitiative.org/sites/default/files/eHI-HIESurveyResultsFinalReport-2008.pdf
- 20. eHealth Initiative, (2009), "Migrating Toward Meaningful Use: The State of Health Information Exchange", http://www.ehealthinitiative.org/sites/default/files/file/2009%20Survey%20Report%20FINAL.p df

- 21. eHealth Initiative, (2010), "The State of Health Information Exchange in 2010: Connecting the Nation to Achieve Meaningful Use", http://www.ehealthinitiative.org/uploads/file/Final%20Report.pdf
- 22. Goldstein M., Rein A., (2010), "Consumer Consent Options for Electronic Health Information Exchange: Policy Considerations and Analysis". Office of Policy and Planning: Office of the National Coordinator for Health IT.
- 23. Government Accountability Office, (2003), "Homeland Security: Information Sharing Responsibilities, Challenges, and Key Management Issues.", Statement of Robert F. Dacey, Director, Information Security Issues and Randolph C. Hite, Director, Information Technology Architecture and Systems Issues, GAO-03-715T.
- 24. Greenberg, M. D., Ridgely M. S., Hillestad R.J., (2009), "Crossed Wires: How Yesterday's Privacy Rules Might Undercut Tomorrow's Nationwide Health Information Network", Health Affairs 28:2, 450-452.
- 25. Heckman J.J., (1978), "Dummy Endogenous Variables in a Simultaneous Equation System", Econometrica, 46:4, 931-959.
- 26. Hillestad R., Bigelow J., Bower A., Girosi F., Meili R., Scoville R., Taylor R., (2005), "Can electronic medical record systems transform health care? Potential health benefits, savings, and costs", Health Affairs, 24:5,1103-1117.
- 27. Jha A.K., Chan D.C., Ridgway A.B., Franz C., Bates D.W., (2009), "Improving Safety And Eliminating Redundant Tests: Cutting Costs In U.S. Hospitals", Health Affairs, 28:5, 1475-1484.
- 28. McDonald C., (2009),"Protecting Patients In Health Information Exchange: A Defense Of The HIPAA Privacy Rule.", Health Affairs, 28:2, 447-449.
- 29. McGraw D., Dempsey J. X., Harris L., Goldman J., (2009), "Privacy As An Enabler, Not An Impediment: Building Trust Into Health Information Exchange." Health Affairs 28:2, 416-427.
- 30. Miliard M., (2010), "ACLU brings suit against Rhode Island HIE", Healthcare IT News, December 01, 2010, http://www.healthcareitnews.com/news/aclu-brings-suit-against-rhode-island-hie-0.
- 31. Miller A., Tucker C., (2009), "Privacy Protection and Technology Diffusion: The Case of Electronic Medical Records", Management Science, 55:7, 1077-1093.
- 32. Ness R.B., (2007), "Influence of the HIPAA privacy rule on health research", Journal of the American Medical Association, 298:18, 2164–2170.
- 33. OECD, (1980), "Guidelines on the Protection of Privacy and Transborder Flow of Personal Data".

- 34. Pritts, J., Choy, A., Emmart, L. and Hustead, J., (2002), "The State of Health Privacy: A Survey of State Health Privacy Statutes", Georgetown University, Washington, DC, 2002.
- 35. Pritts, J., Goldman, J., Hudson, Z., Berenson, A. and Hadley, E., (1999), "The State of Health Privacy: An Uneven Terrain. A Comprehensive Survey of State Health Privacy Statutes", Georgetown University, Washington, DC, 1999.
- 36. Pritts J., Lewis S., Jacobson R., Lucia K., Kayne K., (2009), "Privacy and Security Solutions for Interoperable Health Information Exchange: Report on State Law Requirements for Patient Permission to Disclose Health Information", Office of Policy and Research: Office of the National Coordinator for Health IT.
- 37. Romanosky S., Telang R., Acquisti A., (2011), "Do data breach disclosure laws reduce identity theft?", Journal of Policy Analysis and Management, 30:2, 256-286.
- 38. Sankar P., Moran S., Merz J.F. Jones N.L., (2003), "Patient perspectives on medical confidentiality: a review of the literature", Journal of General Internal Medicine, 18:659–669.
- 39. Shang S., Seddon P. B., (2000), "A Comprehensive Framework for Classifying the Benefits of ERP Systems". AMCIS 2000 Proceedings. Paper 39.
- Shen J.J., Samson L.F., Washington E.L., Johnson P., Edwards C., Malone A. (2006), "Barriers of HIPAA regulation to implementation of health services research", Journal of Medical Systems, 30:1, 65.
- 41. Simon S., Evans J.S., Benjamin A., Delano D., Bates D.W., (2009), "Patients Attitudes Toward Electronic Health Information Exchange: Qualitative Study", Journal of Medical Internet Research, 11:3, e30.
- 42. Smith R.E., Snyder K.D., (2002), "Compilation of Federal and State Privacy Laws", Privacy Journal.
- 43. Squire P., (2007), "Measuring State Legislative Professionalism: The Squire Index Revisited", State Politics and Policy Quarterly, 7:2, 211–227.
- 44. Stevens M., (2010), "Getting Over HIE Hurdles", March 3, CMIO.com, http://www.cmio.net/index.php?option=com\_articles&view=article&id=21003:getting-over-hiehurdles.
- 45. Walker J., Pan E., Johnston D., Adler-Milstein J., Bates D.W., Middleton B., (2005), "The Value of Health Care Information Exchange and Interoperability", Health Affairs, 24, w10–w18.
- 46. Wright A., Soran C., Jenter C.A., Volk L.A., Bates D.W., Simon S.R., (2009), "Physician attitudes toward health information exchange: results of a statewide survey", Journal of the American Medical Informatics Association, 17:66-70.

State	HIE Promoting Language	Privacy Requirements	Туре	Law Reference
Pennsylvania	The purpose of the PHIX Governance Structure is to perform activities necessary to develop, implement and manage a Statewide health information exchange and other health information technology initiatives within the Governor's Prescription for Pennsylvania.	None	HIE Only	4 Pa. Code § 6.341
North Dakota	The health information technology advisory committee shall make recommendations to the health information technology office for implementing a statewide interoperable health information infrastructure that is consistent with emerging national standards; promote the adoption and use of electronic health records and other health information technologies; and promote interoperability of health information systems for the purpose of improving health care quality, patient safety, and the overall efficiency of health care and public health services.	None	HIE Only	N.D. Cent. Code, § 54- 59-26
Indiana	Define the vision for a statewide health information exchange system to electronically exchange health care	Ensure compliance with the federal Health Insurance Portability and Accountability Act (HIPAA) (P.L. 104-	ProHIE and No Consent	Ind. Code Ann. § 5- 31-6-1 (West) & Ind. Code

Appendix	A: Selected	d Text from	HIE-Specific	<b>Legislation</b>

	information between	191).		Ann. § 5-
	entities in the health care	(2) Protection of		31-6-3
	system, including at least	information privacy.		(West)
	the following	(3) Use of information		
		in the statewide health		
		information exchange		
		system only in		
		accordance with the		
		Iederal Health		
		and Accountability Act		
		(HIDAA) and as		
		(IIIFAA) and as		
		health agonaios		
Maryland	On or before October 1	Evaluate Any changes	ProHIE and	Md Code
iviar yrand	2009 the Commission and	in State laws that are	No Consent	Ann 8 19-
	the Health Services Cost	necessary to protect the		143 (West)
	Review Commission shall	privacy and security of		&
	designate a health	health information		Md Code
	information exchange for	stored in electronic		Ann 8 19-
	the State	health records or		143
		exchanged through a		_
		health information		
		exchange in the State		
Rhode Island	There shall be established a	(b) Patients and health	ProHIE and	R.I. Gen.
	statewide HIE under state	care providers shall	Consent	Laws § 5-
	authority to allow for the	have the choice to		37.7-4
	electronic mobilization of	participate in the HIE,		(West)
	confidential health care	as defined by the Act		
	information in Rhode	and these Regulations.		
	Island. Confidential health	Patients shall agree to		
	care information may only	participate by signing		
	be accessed, released or	an authorization form		
	transferred from the HIE in	provided by the HIE.		
	accordance with this			
	chapter.		D 1115 1	
Alaska	The department shall	(c) The department	ProHIE and	Alaska
	establish and implement a	shall establish	Consent	Stat. §
	statewide electronic health	procedures for a		18.23.300
	information exchange	patient who is the		& Alaska
	system and ensure the	subject of a health		Stat. §
	interoperability and	record contained in the		18.23.310
	with state and federal	(1) to out out of the		
	with state and rederal	(1) to opt out of the		
	specifications and protocols	(2) to concert to the		
1	101 exchanging nearth	(2) to consent to the	1	1

	records and data	distribution of the		
		patient's records		
		contained in the		
		system;		
New Mexico	None	A provider or health	Privacy Only	N.M. Stat.
		care institution		Ann. § 24-
		participating in a		14B-6
		health information		(West
		exchange using a		1978)
		record locator service		
		shall not have access to		
		demographic		
		information,		
		information about the		
		location of the		
		individual's electronic		
		medical records or		
		information in an		
		individual's electronic		
		medical record except		
		in connection with the		
		treatment of the		
		individual or as		
		permitted by the		
		consent of the		
		individual or as		
		otherwise permitted by		
		state or federal law.		
Maine	None	A health information	Privacy Only	Me. Rev.
		exchange to which		Stat. Ann.
		health care information		tıt. 22, §
		is disclosed under this		1711 <b>-</b> C
		paragraph shall provide		
		an individual		
		protection mechanism		
		by which an individual		
		may prohibit the health		
		information exchange		
		from disclosing the		
		individual's health care		
		information to a health		
		care practitioner or		
1		health care facility;		

# Appendix B: Instrumental Variables and our Cross-Sectional Analysis

To address some of endogeneity concerns in our cross-sectional analysis, we considered using instrumental variables (IV). Ideally, we would like to identify instruments that are correlated with state health privacy sensitivities but uncorrelated with potential confounding variables. For this analysis, we used instruments proposed by Miller and Tucker (2009), which are measures of state opposition to the federal Real ID<sup>4</sup> initiative and the percent of households in a state that subscribe to the "Do Not Call" List.<sup>5</sup> We also introduce a new instrument for this analysis, which is whether a state has passed a law prohibiting employer discrimination based on sexual orientation. This instrument differs from our other instruments in that it does not have a direct privacy link. However, the passage of employee discrimination laws may be correlated with state health privacy protections due to underlying consumer protection sentiments in a state (employees and patients in this case).

We posit that these instruments are correlated with privacy sensitivities in a state (including health privacy), but are likely uncorrelated with potential confounding elements. These include both general state characteristics and healthcare specific attributes such as health technology adoption in a state (e.g. Electronic Medical Records), state funding provided to HIEs, and general attitudes towards the healthcare sector. Our IV's are strongly predictive of state propensity to have health disclosure legislation with our first stage evaluations of our instruments showing joint F-stats between 11.12-13.76 based on the specification.

The claim that our IV's are uncorrelated with potential confounds to our analysis is not trivial as we may be concerned that our IVs are correlated with state characteristics that also drive HIE outcomes. For example, we may argue that both our health disclosure laws and IVs are correlated with educational levels in a state, which is in turn is the true driver of the HIE outcomes in a state. We investigate this argument and find that indeed our IVs are correlated with state educational levels. However, educational outcomes are also very highly correlated with our *PerCapitaGDP* control and other covariates and are thus are captured in our model. In fact, inclusion of measures of advanced degrees in our model does not provide any additional predictive power with respect to HIE activities.

<sup>&</sup>lt;sup>4</sup> We thank Hal Varian and Fredrik Wallenberg for sharing the data with us.

<sup>&</sup>lt;sup>5</sup> These data come from the ACLU website http://www.realnightmare.org.

We may also be concerned that our IV's could be correlated with the age structure in a state. This may be relevant as healthcare costs are skewed heavily towards the higher ages with a large portion of an individuals healthcare expenses coming later in life. This shift in healthcare costs may in turn drive motivations and incentives for HIE development. Using a measure of the percent of the population over 65, we actually do not find strong support for a correlation between the age structure and our IV's. Additionally, when we include the measure of "individuals over 65" in our model it does not provide any additional predictive power.

Further, we may be concerned that two of our IVs and health disclosure laws are both legislative actions, which may all be driven by underlying state legislative tendencies. These same tendencies could be driving other legislation that is encouraging and driving HIE outcomes. We find a weak correlation between health disclosure laws and HIE promoting legislation so this initial claim is not supported by our data. Further, we included in our model a measure of state legislative professionalism proposed by Squire (2003). We find that this measure is highly correlated with state population measures and its inclusion did not improve our fit or add predictive power. Also, propensity to legislate may also be clustered around political ideology and the role of government in various aspects of life, which should at least be partially controlled for with our "Democratic State" Dummy.

Lastly, we may argue that our some of our IVs may be correlated with the technological sophistication of a state. This is somewhat supported as we find that state "Do Not Call List" participation is positively correlated with the measure of broadband access in a state (which is a control in our model). We also considered various measures of state computer services GDP to help capture state technological sophistication, but found that they did not provide any additional predictive power.

The results of our IV analysis are presented in Table 5 below:

Table 5: I	Results fi	rom IV Aı	nalysis for	r Various	Dependent	Variables
			•		1	

Total HIE	Operational HIE	Failed HIE	Operational Rate	Failure Rate

Disclosure Law	0.691	1.491	-0.047	0.513	-0.421
	(1.49)	(1.91)*	(0.07)	(2.25)**	(1.83)*
Population	0.199	0.179	0.226	0.006	0.001
	(6.37) ***	(2.56)**	(3.31) ***	(0.20)	(0.02)
<b>Population Sq</b>	-0.004	-0.004	-0.004	-0.000	0.000
	(5.33) ***	(2.05)**	(2.62) ***	(0.28)	(0.89)
Blue	-0.103	0.178	-0.479	0.159	-0.154
	(0.47)	(0.42)	(1.19)	(0.84)	(0.80)
<b>Broad Access</b>	0.003	-0.028	0.037	-0.006	0.017
	(0.28)	(0.74)	(1.48)	(0.35)	(0.76)
Per Capita GDP	0.008	0.009	0.003	-0.002	-0.002
	(3.07) ***	(1.49)	(0.69)	(0.25)	(0.22)
Ν	51	51	51	312	312
* significant at 10%					

In any case, IV analysis comes with some restrictive assumptions coupled with a heavily reliance on the validity of these assumptions to ensure identification of causal effects. Challenges to these assumptions should be evaluated based on their general merit and supporting empirical evidence.