Privacy Protection, Personalized Medicine and Genetic Testing

Amalia R. Miller* and Catherine Tucker‡

February 1, 2015

Abstract

This paper explores how state genetic privacy laws affect the diffusion of personalized medicine, using data on genetic testing for cancer risks. State genetic privacy laws take three alternative approaches to protecting patient privacy: Requiring informed consent on the part of the individual; restricting discriminatory usage of genetic data by employers, health care providers or insurance companies; or limiting redisclosure without the consent of the individual or defining genetic data as the 'property' of the individual. We find empirically that approaches to genetic and health privacy that give users control over redisclosure encourage the spread of genetic testing, but that the informed consent approach deters individuals from obtaining genetic tests. We present some evidence that the latter reflects costs imposed on the supply of genetic testing by hospitals. We find no effects of state or federal genetic anti-discrimination laws on genetic testing rates.

*Economics Department, University of Virginia, Charlottesville, VA, IZA and NBER.

†MIT Sloan School of Management, MIT, Cambridge, MA and NBER.

‡We thank the CDC for providing access to the confidential NHIS data used in this study and Alex Marthews for constructing databases with EEOC claims counts and state genetic privacy laws. We thank the NSF for research funding and Scott Laughery for excellent research assistance. The findings and conclusions in this paper are those of the authors and do not necessarily represent the views of the Research Data Center, the National Center for Health Statistics, the Centers for Disease Control and Prevention, or the National Science Foundation.

1 Introduction

Personalized medicine, where patients receive individually tailored health treatment based on their unique genetic makeup, promises to revolutionize healthcare. Clinical applications of genetic information can improve public health and medical care productivity by targeting preventive care and interventions where they are most effective.[1] At the same time, as more links are uncovered between genes and personality traits and future health risks, individuals may suffer from discrimination or other harms from having parts of their genetic information revealed to others.[2] Therefore, the spread of potentially revolutionary genetic tests that form the basis of customized medicine may be stymied by privacy concerns.[3]

This research studies the effects of privacy regulations that are designed to protect genetic privacy on the diffusion of personalized medicine. Strong privacy protection may increase the value of genetic testing to consumers because it assures that they will not suffer harm in future market interactions. However, privacy protection may sensitize consumers to privacy concerns, increase costs to providers of genetic testing services and reduce the value to insurance companies of covering the service. This makes the empirical effect ambiguous. Further, since privacy protection is not a binary, all-or-nothing, choice, it is important to understand which features of privacy regulations are most beneficial from the view of consumers and which are most costly to producers. The study therefore explores the different provisions within privacy laws to identify policies that are most favorable to the spread of personalized medicine. We use variation in state laws over time in the United States to estimate the effect

[1]The potential value of personalized medicine is reflected President Obama's Precision Medicine Initiative, announced in his 2015 State of the Union Address, to which his 2016 budget allocates $215 million. See `http://www.whitehouse.gov/the-press-office/2015/01/30/fact-sheet-president-obama-s-precision-medicine-initiative`.

[2]Komarova et al. (2013) emphasizes the ability of firms to combine multiple different types of public data to identify allegedly anonymous profiles.

[3]Indeed, for the case of cancer risks where genetic links are well-established, and for high-risk populations and therefore genetic testing is most valuable, rates of adoption remain low. Data from the 2010 National Health Interview Survey suggests that, even among individuals who have been advised by their physician to obtain a genetic test for cancer, over 30% do not comply.

of different kinds of genetic privacy laws on the use of genetic testing for cancer risks.

State genetic privacy laws, at a high level of generality, take three alternate approaches to protecting patient privacy: First, requiring informed consent on the part of the individual; second, explicitly restricting the use of genetic data by health insurance, employers or providers of long-term life care or insurance; third, limiting redisclosure without the consent of the individual or defining genetic data as the 'property' of the individual.

Using individual-level panel data, we find that an approach which gives users control over redisclosure encourages the spread of genetic testing, whereas an approach of informed consent deters individuals from obtaining genetic tests. We find no effects of anti-discrimination rules that limit the use of genetic information in particular contexts.

We check the robustness of these results in multiple ways. We show robustness to functional form, different sets of controls, and different treatment of the federal genetic privacy law. We also show that there are no similar effects of genetic privacy protection on non-genetic opt-in health testing (for HIV status) or use of preventive health care (getting a flu shot). We find larger effects for patients where the potential risks of genetic data being misused are highest, such as those who already know they have an elevated risk due to a family history of cancer (and individuals who show greater concern for their health privacy in other ways), but no effects for individuals who have already received a cancer diagnosis for one of the types predicted by genetic testing (breast, ovarian, colon or rectal). We show that the magnitude of the effect of the laws is driven by that individual's stated privacy concerns.

We then evaluate whether these results are driven by individual responses to privacy concerns, or by underlying changes in supply-side testing availability due to the laws. Genetic consent laws appear to reduce testing availability, suggesting that part of their negative effect stems from costs that complying with consent requirements impose on hospitals. However, there is no positive effect on genetic testing availability as a result of redisclosure laws,

suggesting that that particular kind of law derives its positive effect from its ability to provide consumer-side reassurance.

This research has three major contributions.

The first contribution is to build on an existing academic literature on genetic testing and relate it to privacy regulation. Building on theoretical models of the effects of genetic testing on insurance markets such as Strohmenger and Wambach (2000), the empirical economics literature on genetic testing aims to disentangle its inherent implications for asymmetric information on outcomes in insurance markets (Zick et al., 2000, 2005; Armstrong et al., 2003; Oster et al., 2010).[4] Our paper complements these papers by asking how different approaches to restricting sensitive genetic information flows affect genetic testing rates.

The second contribution of this work is to provide some of the first empirical evidence about the need for 'genetic exceptionalism.' There has been substantial policy debate about whether genetic health data are distinct and different from regular health data and therefore needs a special class of protection (Yesley, 1998).[5] Genetic information can reveal more than a person's current health status; it contains information about their future health risks and traits that are unrelated to disease (Savitz and Ramesar, 2004). These concerns, specific to genetic (or genomic) information, can complicate the legal and ethical issues surrounding disclosure of personal information (Berry, 1997), and are the motivation for the new, targeted laws. Reflecting this, the new genetic privacy regulations that we study are explicitly incremental to existing state and federal laws protecting the privacy of personal health information.[6] Our research provides the first empirical evidence on how individual

[4]Oster et al. (2013) discusses a possible psychological motivation for individuals with elevated risks for Huntington's disease to decline genetic testing, namely that a positive result limits their ability to maintain optimistic beliefs about their true risk.

[5]With respect to privacy, Washington is the only state that explicitly treats genetic information the same as other health information by including genetic information in the definition of health care information under the state health privacy law.

[6]Generally, the focus of these laws have been on data privacy rather than data security; see Miller and Tucker (2011b) for a description of the role of data-breach notification laws on the spread of information technology in healthcare.

behavior responds to regulations that protect the privacy of genetic information rather than general health data. Our finding that genetic privacy laws have distinct effects above and beyond standard health data privacy laws provides some support for the need for separate legislative action.

The third contribution is to help provide evidence for policymakers trying to determine the best approach to regulating genetic privacy, given the perceived desirability of personalized medicine. This perceived desirability stems both from the fact that personal genetic information may one day be used by individuals to anticipate their disease risks, select investment in preventive care, and when facing illness, to select the most effective treatment, but there are also potentially large system-wide gains from analyzing personal genetic data on a large scale.

Public health and consumer advocates have argued for strong genetic privacy protections (Gostin, 1991; McEwen and Reilly, 1992; Natowicz et al., 1992; Ostrer et al., 1993). However, life insurance industry representatives have argued that all genetic information from applicants should be made available to them and that genetic insurance might be a viable solution (McEwen et al., 1993; Tabarrok, 1994). By measuring the effects of genetic privacy on genetic testing rates and availability, this paper provides the first empirical evidence on how public policy related to privacy affects the diffusion of genetic medicine. Generally, the empirical literature on privacy regulation has documented largely negative effects of privacy regulation for the spread and use of data-enriched technologies both in healthcare and elsewhere (Miller and Tucker, 2009, 2011a; Goldfarb and Tucker, 2011, 2012a). This paper adds to this literature by not only studying a context where privacy concerns are paramount but also by emphasizing how different features of privacy regulation, in particular those that emphasize rights over data, can have different effects from more commonly found consent requirements, which previous studies have found to be associated with negative effects.

2 Data

2.1 Healthcare Data

To study an individual's likelihood of obtaining genetic testing, we use the National Health Interview Surveys (NHIS) distributed by the National Center for Health Statistics (NCHS), part of the Centers for Disease Control and Prevention (CDC). In particular, we use data in the Cancer Control Modules. These modules include questions about genetic testing for cancer risk, as well as a variety of other screening and preventive care measures and health outcomes. To our knowledge, this is the only source of national data on genetic testing rates for any medical purpose. Genetic testing data are available in 2000, 2005, and 2010, with about 30,000 survey responses in each wave. After excluding observations with missing data, our final sample size is 81,543. Table 1 lists summary statistics for these data. Following NCHS guidance, summary statistics and regression coefficients are computed using person weights from the NHIS.[7]

Genetic tests can be extremely valuable to individuals in certain sub-populations. Genetic variations have been identified that predict increased risks of breast cancer, ovarian cancer, colon cancer, cystic fibrosis, among other diseases. A negative result would imply a normal cancer risk, while a positive result would be elevated. For example, the official guidance for someone who has tested positive for the BRCA or BRCA2 mutation which elevates the risk of breast or ovarian cancer is that they should be offered 'enhanced screening' to try and detect breast cancer at an early stage.[8] It also suggests they also should be offered Prophylactic Surgery which removes as much 'at-risk' tissue as possible, this may involve a double mastectomy and the removal of ovaries and fallopian tubes. There is also the possibility of 'Chemoprevention' which is the use of drugs such as tamoxifen and raloxifene

[7] Weighting is used to adjust for non-random sample selection, survey non-response, and post-stratification in order to compute values that are representative of the civilian noninstitutionalized population of the United States.

[8] `http://www.cancer.gov/cancertopics/factsheet/Risk/BRCA`

to try and reduce the risk of cancer. Though medical evidence is of an early-stage on the effectiveness of such actions there is evidence that taking these aggressive measure can greatly reduce the incidence of cancer. For example, studies suggest that Tamoxifen can breast cancer incidence among healthy BRCA2 carriers by 62% (**?**). A double mastectomy can reduce breast cancer incidence by 90% (Hartmann et al., 2001).

The main focus of our study is whether or not these survey respondents reported that they had a genetic test to ascertain their cancer risk. The average testing rate is 0.54%. Over the sample period, genetic testing rates did increase steadily, from 0.38% of respondents responding positively in 2000 to 0.66% doing so in 2010. Nevertheless, given the progress that has been made in personalized medicine, this low rate of penetration is striking.

The NHIS also contains individual-level information on a variety of health variables as well as background economic and demographic information, which we use as controls. Because the public use version of the NHIS files contain only limited geographic information at the region level (Northeast, Midwest, South, West), in order to conduct our analysis relating genetic testing to state privacy laws, we needed to use restricted geographic information from the NHIS to merge with privacy laws at the state level. We accessed the restricted NHIS data at the CDC's NCHS Research Data Center.

The primary benefit of the NHIS data is that it uniquely allows us to observe actual testing rates in the population. To the best of our knowledge, no other nationally representative datasets exist on genetic testing for the US population. The secondary benefits are that we observe testing rates for a nationally representative sample of high-risk individuals, and more generally, that we can link genetic testing information with a wide range of individual and geographic controls. One issue with our data is that it does not allow us to address directly new markets that have opened up recently where genetic testing is offered by non-local providers or direct-to-consumer testing companies that are not based at healthcare

Table 1: Genetic Testing Information and State Laws: Summary Statistics

	Mean	Std. Dev.
Genetic Test	0.0054	0.073
Heard of Genetic Testing for Cancer Risk	0.43	0.50
Age	45.3	17.5
Female	0.52	0.50
White	0.82	0.39
Black	0.11	0.32
Private Insurance	0.68	0.47
No Insurance	0.17	0.37
Family Cancer	0.38	0.48
Ever Had Testable Cancer Diagnosis	0.019	0.14
State Uninsured	14.4	4.40
State Private Insurance	69.1	7.39
State Medicare	14.1	2.11
State Medicaid	13.0	3.75
State GDP (000)	41.2	7.54
Genetic Consent Law	0.29	0.45
Genetic Anti-Discrimination Law	0.89	0.31
Genetic Redisclosure Law	0.52	0.50
Health Privacy Disclosure Law	0.80	0.40
HIV Test	0.35	0.48
Flu Shot	0.23	0.42

81,453 observations. Individual information from the NHIS (2000, 2005, 2010). State health insurance from the CPS and GDP from the BEA. Testable cancers are defined based on the most commonly reported genetic tests for cancer risks: breast, ovarian, colon, and rectal cancer. Privacy laws described in the text. Means and standard deviations computed using final person weights from the NHIS.

facilities.[9]

2.2 Privacy Laws

Most state legislatures have taken steps to safeguard genetic information beyond the protections provided for other types of health information. A survey of the current state of genetic privacy regulation is provided in Pritts et al. (2009), which provides a useful starting point but lacks the historical information needed for our analysis. To build on this initial data, we investigated changes in genetic privacy laws in each state over time to construct a panel database of state genetic privacy laws relating to the collection, distribution, or use of

[9]Examples of such companies include `23andme.com`. The U.S. Food and Drug Administration (FDA) regulates genetic testing for health risk and has intervened in the direct-to-consumer genetic testing market. In November 2013, the FDA issued a warning letter to the company 23andMe and directed them to stop marketing health-related genetic tests directly to consumers.

genetic information.

There is substantial variation in the timing and the content of state genetic privacy laws, and we exploit this variation to define three categories of genetic privacy laws.

The first category of laws relate to consent for collecting and storing genetic information. Specifically, laws in seventeen states require informed consent for a third party either to perform or require a genetic test or to obtain genetic information. Consent rules for genetic testing may reassure patients by providing clear information on costs and benefits of testing, but could also increase privacy concerns by making them more salient.

The second category includes laws that are explicit anti-discrimination laws which prevent the discriminatory use of genetic data. These laws can target employers or life, long-term care, disability, or health insurers. Anti-discrimination laws will only increase testing if patients are aware of them and believe that they will be effectively enforced. Anti-discrimination laws limit how genetic information is *used* by certain types of organizations that receive it (insurers or employers), but not whether or not they receive the information, so such laws may provide less privacy assurance to consumers than do laws that limit redisclosure and provide ownership rights to patients. On the other hand, since laws are targeted at contexts where privacy fears are greatest, they prove effective at reassuring patients.

The third category consists of laws that give the individual explicit ownership rights over their data by either requiring their consent any time data are disclosed to a third party, or by giving them actual ownership rights over the data.[10] Twenty-seven states require consent to disclose genetic information later. Alaska, Colorado, Florida, Georgia, and Louisiana explicitly define genetic information as personal property. Alaska is unusual in also extending personal property rights to DNA samples. These laws are of interest to economists as they extend a Coasian approach used for example to correct environmental externalities to the

[10]In this paper, we use the terms disclosure and redisclosure interchangeably. The former refers to sharing of information by the original data creator or collector; the latter refers to sharing of data that was received from another party (such as an insurance company sharing data received from a medical provider).

privacy arena. Since there is debate over whether asserting property rights in general can correct market failures in practice, there is ambiguity over how effective such laws will be.

In any empirical study based on panel data such as ours, an important question is where these changes in state laws originate from and could the impulses that led to their enactment also jointly determine medical genetic testing rates. In general, it is hard to identify a common motivation for enactment of such laws even for those who are experts in the field. For example, Sara Katsanis, a research associate at the Duke Institute for Genome Sciences & Policy states, "The laws are all very sparse and random" (Gardner, 2014). Most media reporting surrounding the enactment of new regulation emphasize fears of "genetic McCarthyism" in general and often describe cases where police officers secretly collecting genetic samples without the consent of other individuals (Green and Annas, 2008; Vorhaus, 2011) to give context to the laws. We found little discussion of medical treatment except for passing reference to commercial genetic testing providers such as 23andme.com in the discussion of the laws. Though this is very much anecdotal evidence, it certainly is not positive evidence that there is a connection between the enactment of laws and underlying medical demand for the kind of hospital-based genetic testing that we study.

In Table 1, we show summary statistics on these three broad categories of laws on the NHIS sample we use for the genetic testing analysis. Summary statistics on these laws for the sample of hospitals we use for the analysis of technology availability in Section 3.6 are in Table A-2.

Though we focus on variation in regulation at the state level, there were changes at the federal level in the time period we study. The 2008 Federal Genetic Information Nondiscrimination Act (GINA) provides privacy protection that is specific to genetic information and that covers all states. This Act strengthened the federal protection for genetic information in place since 1996, when it became illegal to deny group health insurance coverage to someone

based on their genetic information.[11] GINA further restricts the use of genetic information by health insurers and employers. In that case, state laws that offer additional protections may reassure patients as to how their information will be used, and thereby increase demand for genetic testing incrementally above the effects of GINA. We address the question of GINA in a separate specification which incorporates how GINA may have changed the baseline protections given at the state-level.

3 Analysis of Genetic Privacy Laws and Genetic Testing

3.1 Initial Results

Table 2 shows our initial results when we examine the effects of our three different categories of laws as well as the effects of general health privacy laws that limit redisclosure. We first examine each variation of law separately and then account for correlated adoption between multiple laws and estimate our main model that includes all of the laws together. In each case, the specification includes numerous individual and state-level controls as well as state and year fixed effects.

In Column (1), we look at the category of regulation that mandates some form of informed consent in isolation from other laws. There is a negative and significant effect on the decision to undergo genetic testing.[12] This is consistent with an economic model where the consent requirement imposes a transaction cost on the provider or consumer. The negative reaction to informed consent rules may also reflect that individuals may be overly optimistic about the amount of their private information that is being collected and used by firms (Jolls, 2007).[13]

Column (2) investigates the effect the presence of an anti-discrimination law in isolation

[11] GINA affirms that genetic information is considered private health information and that protections relating to confidentiality and security in the Health Information Portability and Accountability Act (HIPAA) Privacy Rule apply equally to genetic data.

[12] In separate estimation, we decomposed this result and found that, while both requiring explicit consent for testing and consent for retaining genetic information have negative effects on genetic testing, it is the requirement to collect informed consent in general that has the most statistically significant relationship

Table 2: Initial Results

	(1)	(2)	(3)	(4)	(5)
Genetic Consent Law	-0.0039**				-0.0045***
	(0.0017)				(0.0013)
Genetic Anti-Discrimination Law		0.0010			0.00084
		(0.0019)			(0.0014)
Genetic Redisclosure Law			0.000057		0.0037**
			(0.0013)		(0.0016)
Health Privacy Disclosure Law				0.0033***	0.0030***
				(0.00085)	(0.00081)
Age	0.0000078	0.0000077	0.0000076	0.0000082	0.0000082
	(0.000016)	(0.000016)	(0.000016)	(0.000016)	(0.000016)
Female	0.0027***	0.0027***	0.0027***	0.0027***	0.0027***
	(0.00062)	(0.00062)	(0.00062)	(0.00062)	(0.00062)
White	0.00098	0.0010	0.00100	0.00094	0.00095
	(0.00093)	(0.00093)	(0.00093)	(0.00092)	(0.00092)
Black	0.0024**	0.0024**	0.0024**	0.0024**	0.0024**
	(0.0010)	(0.0010)	(0.0010)	(0.0010)	(0.0010)
Family Cancer	0.0051***	0.0051***	0.0051***	0.0051***	0.0051***
	(0.00085)	(0.00085)	(0.00085)	(0.00085)	(0.00085)
Private Insurance	-0.0011	-0.0011	-0.0011	-0.0011	-0.0011
	(0.00082)	(0.00082)	(0.00082)	(0.00082)	(0.00082)
No Insurance	-0.0020*	-0.0020*	-0.0020*	-0.0020*	-0.0020*
	(0.0011)	(0.0011)	(0.0011)	(0.0011)	(0.0011)
State Uninsured	0.000086	-0.00022	-0.00017	-0.000089	-0.000020
	(0.00057)	(0.00058)	(0.00059)	(0.00057)	(0.00058)
State Private Insurance	-0.000053	-0.00030	-0.00025	-0.00021	-0.00019
	(0.00042)	(0.00048)	(0.00047)	(0.00040)	(0.00042)
State Medicare	0.00034	0.00020	0.00021	0.00020	0.00034
	(0.00047)	(0.00043)	(0.00043)	(0.00041)	(0.00046)
State Medicaid	0.00033	0.000084	0.00013	0.00017	0.00026
	(0.00043)	(0.00046)	(0.00046)	(0.00041)	(0.00041)
State GDP (000)	0.00022	0.00026	0.00026	0.00026	0.00020
	(0.00023)	(0.00026)	(0.00025)	(0.00025)	(0.00024)
State Fixed Effects	Yes	Yes	Yes	Yes	Yes
Year Fixed Effects	Yes	Yes	Yes	Yes	Yes
Observations	81543	81543	81543	81543	81543
Log-Likelihood	97399.8	97397.8	97397.7	97401.1	97403.3

OLS estimates. Dependent variable is decision to take genetic test for cancer risks. Omitted race category includes Asian, Native American, Other and Multiple. All regressions use NHIS final person weights. Robust standard errors clustered at the state level. * $p < 0.10$, ** $p < 0.05$,*** $p < 0.01$

on genetic testing rates. This is a law that prohibits discrimination by employers, life insurance companies or health insurance companies based on genetic information. We find no statistically significant relationship.[14] The general lack of an effect of anti-discrimination laws is consistent with several possibilities. It could be that the laws are too limited in scope or enforcement to assuage consumer concerns. Or, it could be that consumers are already able to effectively protect the privacy of their genetic test results from employers or insurers by paying out of pocket for testing. It is also possible that the laws have offsetting effects that lead to zero overall effect. Anti-discrimination rules may increase the willingness of consumers to undergo testing while at the same time decrease the willingness of health insurers (or employers in the case of employment-based self-insured health plans) to cover the tests.

Column (3) investigates the relationship between genetic testing and the presence of a law that requires consent to be given if the data are ever to be shared again. We find a very small and imprecise effect. Column (4) examines the baseline effects of the presence of a general health privacy law. We find a positive and statistically significant relationship between genetic testing and the presence of a general health privacy law that limits disclosure.

Column (5) of Table 2 reports the main estimates in which we study the effects of each of the laws in a single model. For the genetic laws, we find that it is still the case that informed consent requirements have a negative effect, and that anti-discrimination laws have little measurable effect. The positive coefficient on granting property rights over redisclosure is now substantially larger and statistically significant in this specification. The reason for this change is likely the positive correlation between genetic consent and redisclosure laws; not

with genetic testing.

[13] Jolls (2007) discusses this as a possible market failure around workplace privacy that could justify privacy regulation. She notes that these concerns are increasing in importance as information and communication technologies become more widespread.

[14] Separate estimation of different types of anti-discrimination laws relating to health, long-term care insurance and employment again shows no statistically significant relationships.

Table 3: Genetic Privacy Laws and Latent Demand for Genetic Privacy

	Consent Law		Anti-Discrimination Law		Redisclosure Law	
	(1)	(2)	(3)	(4)	(5)	(6)
GINA Filed Per Pop.	-0.042		0.018		0.033	
	(0.031)		(0.020)		(0.033)	
GINA Resolved Per Pop.		-0.048		0.017		0.019
		(0.035)		(0.023)		(0.038)
Constant	0.42***	0.41***	0.86***	0.87***	0.36***	0.41***
	(0.10)	(0.096)	(0.068)	(0.062)	(0.11)	(0.10)
Observations	51	51	51	51	51	51
Log-Likelihood	-32.3	-32.3	-10.1	-10.2	-36.3	-36.6

OLS estimates. State level unit of observation. Dependent variables are indicators for having a genetic privacy law of each type in place in 2008. Explanatory variables are the total numbers of genetic discrimination cases filed or resolved by the EEOC between 2010 and 2012, scaled to state population.
* $p < 0.10$, ** $p < 0.05$, *** $p < 0.01$

accounting for the negative effects of consent rules was biasing the estimate for redisclosure rules downward. As in the previous column, redisclosure limits for health information that are not specific to genetic data are associated with more genetic testing.

When we look at the controls across the columns, in general the estimates are reasonably consistent. Being female, black, or having a family history of cancer positively affect the decision to have a genetic test. Having no insurance (weakly) negatively affects the decision, perhaps because of cost concerns, but there is no significant difference between public and private insurance coverage. State characteristics and the linear age control have no precisely measured effects.

An obvious question for any paper that relies on a panel data setting such as ours is whether there are underlying changes in that state that could explain both the enactment of certain types of genetic privacy law and a change in cancer testing rates, that would not be controlled for using our controls. Such a source of time-varying heterogeneity can provide an alternative explanation of our results. One potential source of bias that would lead us to under-estimate the effect of anti-discrimination rules is if states where discrimination is more likely (more precisely, at the time when discrimination risk is increasing) are more likely to pass rules banning genetic discrimination.

We explored this possibility using a cross-sectional measure of state-level latent "demand" for anti-discrimination rules based on enforcement of the federal anti-discrimination law, GINA. To conduct this analysis, we obtained data from the Equal Employment Opportunity Commission (EEOC) on counts of discrimination charges filed and resolved under GINA for fiscal years 2010 to 2012. We found no significant relationships between these measures of privacy demand (measured as charges filed or resolved per population) and the presence or timing of any of the genetic privacy rules we study. Table 3 shows the insignificant correlations for having a law by 2008. Estimates are also insignificant if earlier years are used or if the total share of years with a law in place between 1998 and 2008 is used (see Table A-1). The general lack of significance, combined with the inconsistent direction of the point estimates (where GINA claims are positively associated with anti-discrimination and re-disclosure laws but negatively with consent laws), is supportive evidence that the variation in state genetic privacy laws we study is not motivated by the populations' underlying privacy preferences towards genetic testing. This is consistent with anecdotal evidence on the "randomness" of the laws discussed in Section 2.2.

3.2 Robustness Checks

Table 4 presents a series of robustness checks for Table 2. Columns (1) and (2) report robustness checks to different sets of controls. Column (1) shows that our results hold when we do not use any state or demographic controls. Column (2) adds non-linear age controls.

Column (3) of Table 4 explores whether explicitly incorporating the changes in federal law resulting from GINA affects our estimates. GINA explicitly prohibited discrimination in health insurance coverage and employment based on genetic information. Therefore, we modified our indicator variable to reflect this blanket federal coverage for the 2010 sample. However, the general pattern of these laws not appearing to have a statistically significant relationship with genetic testing decisions continues.

Table 4: Robustness Checks

	Controls		GINA	Probit
	(1)	(2)	(3)	(4)
Genetic Consent Law	-0.0038***	-0.0045***	-0.0046***	-0.33***
	(0.0013)	(0.0013)	(0.0014)	(0.089)
Genetic Anti-Discrimination Law	0.00091	0.00083		0.00014
	(0.0015)	(0.0014)		(0.13)
Genetic Redisclosure Law	0.0032**	0.0037**	0.0047**	0.39**
	(0.0013)	(0.0016)	(0.0017)	(0.16)
Genetic Anti-Discrimination (GINA)			-0.0020	
			(0.0018)	
Health Privacy Disclosure Law	0.0030***	0.0030***	0.0029***	0.17**
	(0.00089)	(0.00081)	(0.00086)	(0.068)
Age 35-50		-0.00015		
		(0.00072)		
Age > 50		0.00054		
		(0.00070)		
Female		0.0027***	0.0027***	0.19***
		(0.00062)	(0.00062)	(0.044)
White		0.00093	0.00093	0.075
		(0.00092)	(0.00092)	(0.074)
Black		0.0024**	0.0024**	0.18**
		(0.0010)	(0.0010)	(0.076)
Family Cancer		0.0051***	0.0051***	0.32***
		(0.00087)	(0.00085)	(0.038)
Private Insurance		-0.0010	-0.0011	-0.068
		(0.00081)	(0.00082)	(0.044)
No Insurance		-0.0019*	-0.0020*	-0.14**
		(0.0010)	(0.0011)	(0.069)
State Uninsured		-0.000021	0.000095	0.036
		(0.00058)	(0.00056)	(0.049)
State Private Insurance		-0.00019	-0.000062	0.0051
		(0.00042)	(0.00040)	(0.036)
State Medicare		0.00034	0.00043	0.033
		(0.00046)	(0.00042)	(0.034)
State Medicaid		0.00026	0.00035	0.029
		(0.00041)	(0.00041)	(0.031)
State GDP (000)		0.00020	0.00019	0.013
		(0.00024)	(0.00023)	(0.018)
Age			0.0000081	0.00080
			(0.000016)	(0.0011)
State Fixed Effects	Yes	Yes	Yes	Yes
Year Fixed Effects	Yes	Yes	Yes	Yes
Observations	81543	81543	81543	80817
Log-Likelihood	97329.9	97403.8	97404.1	-2611.2

OLS estimates except for final columns which presents results from a Probit specification. Dependent variable is decision to take genetic test for cancer risks. All regressions use NHIS final person weights. Robust standard errors clustered at the state level. * $p < 0.10$, ** $p < 0.05$, *** $p < 0.01$

Column (4) of Table 4 shows robustness to a probit functional form that reflects explicitly the binary nature of the decision. The sample size is smaller because some states are dropped (for lack of variation in the outcome). The results are qualitatively unchanged. The table reports probit coefficients. Marginal effects on the laws have the same sign and statistical significance.

3.3 Falsification and Behavioral Checks

We now return to explore further the concerns that motivated the analysis in Table 3 - that there is time-varying heterogeneity that may jointly determine state genetic privacy laws and genetic testing in that state. In this section, we use variation in the NHIS data to show that the effects of privacy laws are larger when we focus on populations for whom genetic testing is more relevant. We also show no effects of genetic privacy for opt-in health actions that are not genetic tests. This provides some reassuring evidence that the effect we are studying is driven by the laws themselves, rather than something else. These tests are particularly useful in our setting because the limited time variation (with only 3 survey waves) precludes a traditional falsification test based on pre-trends in outcomes.

Columns (1) and (2) of Table 5 explore what happens when we restrict our sample to subsamples for whom genetic testing may be of greater interest. The first population is those who report that they are aware of genetic testing. Testing rates are 1.4% overall for those who report having heard of genetic tests, increasing from 1.1% to 1.7% over the period; they are zero for those who have not heard of the tests. The second is a subsample of females. We look at this sub-population simply because of the fact that the genetic test for breast cancer is one of the most prevalent. In both of these subpopulations, where there should be more awareness of the benefits of testing, the effect of the genetic privacy laws appears strengthened. The effect of general health privacy laws is larger for the sub-population that is aware of genetic testing but is negligible for the female sample.

Table 5: Mechanism and Falsification Checks

	Heard	Female	Falsification	
	(1)	(2)	(3)	(4)
	Genetic Test	Genetic Test	HIV Test	Flu Shot
Genetic Consent Law	-0.011***	-0.0036**	-0.023	0.020
	(0.0028)	(0.0014)	(0.022)	(0.018)
Genetic Anti-Discrimination Law	0.0013	0.0025	-0.020	0.011
	(0.0034)	(0.0016)	(0.015)	(0.020)
Genetic Redisclosure Law	0.0081**	0.0066***	0.036	0.016
	(0.0035)	(0.0020)	(0.034)	(0.025)
Health Privacy Disclosure Law	0.0082***	0.00073	0.024**	-0.0067
	(0.0024)	(0.0014)	(0.0095)	(0.011)
Age	0.000057	-0.0000021	-0.0070***	0.0071***
	(0.000044)	(0.000028)	(0.00017)	(0.00013)
Female	0.0046***		0.055***	0.031***
	(0.0014)		(0.0046)	(0.0033)
White	-0.0011	0.00069	0.0032	-0.0083
	(0.0029)	(0.0018)	(0.012)	(0.0071)
Black	0.0063**	0.00015	0.17***	-0.040***
	(0.0031)	(0.0022)	(0.015)	(0.0068)
Family Cancer	0.0082***	0.0065***	0.035***	0.0070
	(0.0017)	(0.0012)	(0.0040)	(0.0043)
Private Insurance	-0.0100***	-0.00080	-0.047***	-0.016***
	(0.0026)	(0.0014)	(0.0073)	(0.0055)
No Insurance	-0.0073**	-0.00087	-0.049***	-0.10***
	(0.0032)	(0.0018)	(0.0089)	(0.0057)
State Uninsured	0.00027	-0.0012	-0.0069	-0.0014
	(0.0013)	(0.00090)	(0.0076)	(0.0057)
State Private Insurance	-0.00022	-0.00091	-0.0034	0.0011
	(0.00095)	(0.00070)	(0.0052)	(0.0045)
State Medicare	0.00097	0.00051	0.00058	-0.00017
	(0.0010)	(0.00080)	(0.0048)	(0.0036)
State Medicaid	0.00091	-0.00013	-0.0034	0.00026
	(0.00092)	(0.00071)	(0.0044)	(0.0043)
State GDP (000)	0.00059	0.00027	0.0017	-0.0025
	(0.00056)	(0.00038)	(0.0028)	(0.0020)
State Fixed Effects	Yes	Yes	Yes	Yes
Year Fixed Effects	Yes	Yes	Yes	Yes
Observations	33167	45814	81543	81543
Log-Likelihood	25968.7	49315.5	-51597.5	-39597.2

OLS estimates. Dependent variable is decision to take genetic test for cancer risks in Columns (1) and (2), decision to take HIV test in Column (3) and decision to get a flu shot in Column (4). All regressions use NHIS final person weights. Robust standard errors clustered at the state level. * $p < 0.10$, ** $p < 0.05$, *** $p < 0.01$

Columns (3) and (4) of Table 5 present falsification checks. We first consider testing for HIV status as a dependent variable. This is another opt-in test that could reveal sensitive and private information but that should not be affected by genetic privacy rules, since contracting HIV is not predicted by genetics. The results in Column (3) show that, while genetic testing laws are not significantly related to rates of HIV testing, general health privacy rules tend to increase HIV testing rates. This test addresses the concern that the passage of genetic privacy state laws is connected with underlying state patient preferences for taking health tests rather than a direct causal effect from genetic privacy regulation to the decision to take a genetic test. Column (4) of Table 5 reports the estimates when the dependent variable is having a flu shot. We use this test because having a flu shot and having a genetic test may be similarly motivated in terms of underlying demand for preventative medical measures. For this outcome, neither form of health privacy protection (genetic or general) has a significant effect on use. This placebo check provides evidence against concerns that changes in genetic privacy rules are related to underlying changing in population preferences for health protection or use of preventive care.

3.4 Different Risk Profiles before Genetic Testing

We then turn to consider the extent to which a consumer's knowledge about their risks *ex ante* affects the way that genetic privacy laws influence their demand for testing.

In Table 6, we estimate separate effects of genetic privacy for individuals with different underlying risk profiles. The mutations being tested for are relatively rare, and genetic testing is most informative for individuals with elevated cancer risks. Though there are no established medical criteria for deciding exactly when testing is appropriate, the usual practice is to recommend testing for individuals with a higher chance of possessing the mutation or of being at risk for the disease. For example, testing for genetic mutations such as BRCA1 and BRCA2, which predict breast and ovarian cancer frequency, is recommended

to individuals with a family history of cancer. This greater value is reflected in higher testing rates, positive and significant across all specifications in the previous tables, for individuals who report a family history of cancer (which we define as having a parent or sibling who ever received a cancer diagnosis).

Although it increases the expected informational content of genetic testing, an elevated cancer risk can also increase the expected harm from genetic testing (assuming that the harm occurs if the test result is positive). For that reason, we should expect that individuals with higher self-reported cancer risk to also be more sensitive to the privacy regime. We exploit data collected by the NHIS that categorizes individuals into below average, average, and above average risks for cancer. Comparing the point estimates across the first three columns of Table 6 shows steady increases in effect sizes for people informed about their lower-than-average cancer risk in Column (1), to normal risk in Column (2), to higher than average risk in Column (3). Across the three columns, the effect of genetic consent laws goes from -0.0045 to -0.0066 to -0.014.[15] The effect of genetic redisclosure laws is only positive for the higher risk group (though not precisely estimated on the small sub-sample) and general health privacy laws go from negative to positive 0.0084 to 0.015 as risk increases. Although these estimates are not generally statistically distinguishable, the consistent pattern is suggestive.

A similar pattern emerges in Columns (4) and (5) of Table 6, when we split the sample into individuals with and without any immediate family members (parents or siblings) who have been diagnosed with cancer from one of the four types of cancer risks that individuals in our sample received genetic testing for (breast, ovarian, colon or rectal). Estimates for the sub-sample of individuals with no family history of "testable" cancers are in Column (4). These individuals face lower baseline cancer risk for these cancer types than individuals with such family histories, the sub-sample used in Column (5). The larger point estimates for

[15]This is similar to the pattern of increasing rates of genetic across the columns, going from under 1% for the low and normal risk groups to almost 2% for the high risk group.

genetic consent and genetic redisclosure laws for individuals in the higher risk group (both in absolute terms and relative to the baseline testing rates for the sub-sample) again suggest that individuals with higher risks from genetic tests are more sensitive to genetic privacy rules in their genetic testing decisions.

Column (6) of Table 6 shows that the pattern of increasing responsiveness with increasing cancer risk is no longer present when the risk has been realized and the individual has already received a cancer diagnosis for one of the four testable types of cancer (breast, ovarian, colon or rectal). For this sub-sample, the coefficients on the privacy laws are reversed in sign and not statistically significant (though the small sample size surely contributes to the imprecision of the estimates). In Column (6), age is a negative and significant predictor of genetic testing. This may be because, among individuals with diagnosis, the value of genetic testing is larger when they are younger. Column (7) shows that our overall results from Table 2 are all present on the sub-sample of individuals who have not been diagnosed with a testable form of cancer.

Table 6: Different Risk Profiles

	Low Cancer Risk (1) Genetic Test	Normal Cancer Risk (2) Genetic Test	High Cancer Risk (3) Genetic Test	No Family Testable Cancer (4) Genetic Test	Family Testable Cancer (5) Genetic Test	Had Testable Cancer (6) Genetic Test	No Testable Cancer (7) Genetic Test
Genetic Consent Law	-0.0045**	-0.0066***	-0.014*	-0.0027**	-0.0099**	0.018	-0.0049***
	(0.0021)	(0.0010)	(0.0078)	(0.0012)	(0.0040)	(0.025)	(0.0014)
Genetic Anti-Discrimination Law	-0.0080	-0.0042	-0.034	-0.00019	0.0029	0.024	0.00042
	(0.0049)	(0.0034)	(0.037)	(0.0015)	(0.0056)	(0.027)	(0.0014)
Genetic Redisclosure Law	-0.037	-0.0067	0.068	0.0031	0.0063	-0.060	0.0045***
	(0.050)	(0.0075)	(0.061)	(0.0022)	(0.0059)	(0.040)	(0.0014)
Health Privacy Disclosure Law	-0.062	0.0084**	0.015	0.0038***	0.0014	-0.014	0.0033***
	(0.062)	(0.0037)	(0.022)	(0.00075)	(0.0021)	(0.025)	(0.00076)
Age	0.0000010	0.000024	0.00013	0.000026	-0.000068*	-0.0024***	-0.000023
	(0.000027)	(0.000037)	(0.00012)	(0.000018)	(0.000034)	(0.00069)	(0.000014)
Female	0.0019**	0.0037***	0.010***	0.0015***	0.0064***	0.014	0.0012*
	(0.00074)	(0.0011)	(0.0035)	(0.00051)	(0.0017)	(0.016)	(0.00064)
White	0.00057	0.00035	0.012*	0.0010	-0.00016	0.020	0.00095
	(0.0011)	(0.0025)	(0.0062)	(0.00062)	(0.0045)	(0.034)	(0.00059)
Black	0.00016	0.00076	0.022**	0.0027***	0.00020	-0.013	0.0029***
	(0.0018)	(0.0030)	(0.0095)	(0.00097)	(0.0044)	(0.037)	(0.00077)
Family Cancer	0.0042***	0.0052***	0.0012	0.0032**		0.0093	0.0044***
	(0.0014)	(0.0016)	(0.0041)	(0.0013)		(0.016)	(0.00077)
Private Insurance	-0.0019	0.0020**	-0.0015	-0.0011	-0.0013	0.0046	-0.0014*
	(0.0014)	(0.00087)	(0.0044)	(0.00092)	(0.0020)	(0.011)	(0.00079)
No Insurance	-0.0024	-0.000035	-0.0050	-0.0011	-0.0073***	-0.067**	-0.0018*
	(0.0021)	(0.0016)	(0.0064)	(0.0012)	(0.0024)	(0.027)	(0.0010)
State Uninsured	0.0029**	-0.00065	-0.00021	0.00094	-0.0028*	-0.0084	0.00028
	(0.0012)	(0.0010)	(0.0035)	(0.00059)	(0.0014)	(0.018)	(0.00061)
State Private Insurance	0.0016*	-0.00038	-0.0024	0.00022	-0.0013	-0.0046	-0.0000046
	(0.00084)	(0.00069)	(0.0036)	(0.00044)	(0.0011)	(0.012)	(0.00041)
State Medicare	0.0012	0.00065	-0.0027	0.00059	-0.00025	0.0078	0.00030
	(0.0011)	(0.00061)	(0.0036)	(0.00045)	(0.00096)	(0.013)	(0.00035)
State Medicaid	0.0021**	0.00029	-0.0029	0.00059	-0.00071	0.0012	0.00032
	(0.00094)	(0.00063)	(0.0033)	(0.00044)	(0.00095)	(0.011)	(0.00038)
State GDP (000)	-0.00047	0.000096	0.0019	0.00023	0.000078	0.0019	0.00016
	(0.00056)	(0.00031)	(0.0020)	(0.00020)	(0.00061)	(0.0079)	(0.00016)
State Fixed Effects	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Year Fixed Effects	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Observations	17730	25173	6206	62359	19184	1730	79813
Log-Likelihood	24253.2	31888.4	3532.2	83473.5	17285.1	127.8	103555.3

OLS estimates. Dependent variable is decision to take genetic test for cancer risks. Robust standard errors clustered at the state level.
* $p < 0.10$, ** $p < 0.05$, *** $p < 0.01$

3.5 Demand for Privacy

We then move away from individual fears about what the genetic test may reveal as a potential moderator of the effect, to considering how individual demand for privacy might moderate our results. The NHIS do not explicitly ask about privacy demand, so we use two proxies. The first is based on engaging in privacy-protective behavior in the context of HIV testing. Specifically, we identify a group of individuals that show high demand for health privacy based on their refusing to answer the NHIS question about HIV testing or reporting to the NHIS that they did not provide their complete name when receiving an HIV test. In the first two columns of Table 7, we split the same into those who have engaged in such privacy protective behavior in Column (1) and those who have not in Column (2). The estimated effects of privacy laws are substantially larger for the privacy-protective individuals, by as much as an order of magnitude. This provides suggestive evidence that the effects we measure are driven partially by individual privacy concerns, though in section 3.6 we will show that the consent law effect may also be driven by the supply side.

The second split meant to capture privacy tastes is based on age of the respondent. We find that older individuals react far more negatively to genetic consent laws and react somewhat less positively to redisclosure laws for either genetic or general health information. Speculatively, this pattern would be consistent with older individuals caring more about privacy but at the same time being either more skeptical about the effectiveness of redisclosure rules to protect their privacy or having concerns about both private sector and government reuse of their data. The finding that older individuals care more about privacy reflects findings in other domains (Goldfarb and Tucker, 2012b).

Table 7: Privacy Demand

	Private HIV	None HIV	Under 40	40+
	(1)	(2)	(3)	(4)
	Genetic Test	Genetic Test	Genetic Test	Genetic Test
Genetic Consent Law	-0.046***	-0.0031***	-0.0013	-0.0067**
	(0.013)	(0.0010)	(0.0019)	(0.0028)
Genetic Anti-Discrimination Law	-0.0092	0.00094	-0.0010	0.0021
	(0.021)	(0.0015)	(0.0015)	(0.0022)
Genetic Redisclosure Law	0.016	0.0044***	0.0048*	0.0030
	(0.022)	(0.0016)	(0.0027)	(0.0030)
Health Privacy Disclosure Law	0.019**	0.0024***	0.0051**	0.0014
	(0.0077)	(0.00079)	(0.0022)	(0.0019)
Age	0.0000024	0.000013	0.000081	0.0000023
	(0.00014)	(0.000016)	(0.000070)	(0.000039)
Female	-0.0021	0.0028***	0.0017**	0.0033***
	(0.0046)	(0.00061)	(0.00071)	(0.0010)
White	0.0037	0.00085	0.00088	0.00100
	(0.0054)	(0.00086)	(0.00087)	(0.0015)
Black	0.00060	0.0025**	0.0030**	0.0017
	(0.0049)	(0.0011)	(0.0012)	(0.0014)
Family Cancer	0.0070	0.0050***	0.0064***	0.0045***
	(0.0057)	(0.00083)	(0.0018)	(0.00087)
Private Insurance	-0.017	-0.00050	-0.0031*	-0.00032
	(0.013)	(0.00071)	(0.0016)	(0.00090)
No Insurance	-0.021	-0.0013	-0.0034**	-0.0020
	(0.015)	(0.00090)	(0.0015)	(0.0015)
State Uninsured	0.0020	-0.000073	0.0012	-0.00086
	(0.0025)	(0.00058)	(0.00087)	(0.00086)
State Private Insurance	-0.00060	-0.00015	0.00063	-0.00074
	(0.0017)	(0.00042)	(0.00056)	(0.00063)
State Medicare	0.00084	0.00033	0.00096*	-0.00014
	(0.0035)	(0.00047)	(0.00054)	(0.00068)
State Medicaid	0.0035	0.00018	0.00089	-0.00016
	(0.0025)	(0.00043)	(0.00058)	(0.00061)
State GDP (000)	0.00040	0.00015	0.00033*	0.00011
	(0.00083)	(0.00025)	(0.00018)	(0.00044)
State Fixed Effects	Yes	Yes	Yes	Yes
Year Fixed Effects	Yes	Yes	Yes	Yes
Observations	2993	78550	32183	49360
Log-Likelihood	2601.1	95166.4	42071.2	55715.7

OLS estimates. Dependent variable is decision to take genetic test for cancer risks. Robust standard errors clustered at the state level. * $p < 0.10$, ** $p < 0.05$, *** $p < 0.01$

3.6 Genetic Testing Availability

So far, this paper has focused on how different genetic privacy testing regimes affect consumer decisions to pursue a genetic test. However, the ability of an individual to pursue a genetic test is limited by the supply-side availability of genetic testing. Privacy regulations might also lower the supply of genetic testing by imposing additional compliance costs on healthcare providers that make investment in genetic testing facilities less profitable. Furthermore, restrictions on redisclosure can also lower the financial value to hospitals and laboratories of collecting patients' genetic information and may limit availability. In this section, we ask if the changes in genetic testing rates associated with changes in genetic privacy laws in the NHIS data are coming from changes in testing rates for given levels of availability, or instead, if changes in genetic testing availability at hospitals is the underlying mechanism which can explain our measured effects.

We measure genetic testing availability using hospital-level data from annual surveys compiled by the American Hospital Association (AHA). The AHA data contain information on a variety of services and technological investments. Previous studies that have used AHA data to study hospital technology adoption include Ciliberto (2006), Baker (2001), and Baker and Phibbs (2002). Our research uses information in the AHA survey on the presence of genetic testing and counseling facilities within each individual hospital and within the same health system for our outcome measures. We also use AHA data about the hospital size (staffed beds and inpatient days), revenue sources (share of inpatient days covered by Medicare and Medicaid), and managed care contracts (indicators for having PPO or HMO contracts) to create time-varying hospital-level controls for factors that could affect technology adoption.

The main limitation of the AHA data for our purposes is that genetic testing information is only available starting in 2003. This means that the sample period for this analysis

(2003 − 2010) includes only part of the period of analysis using NHIS data (2000 − 2010). Because of this mismatch, we study testing availability separately rather than estimating a joint model of supply and demand.

The results are reported in Table 8. The estimates in Column (1) are from a hospital-year level regression of genetic testing availability on genetic and other privacy laws, year fixed effects to capture national trends in adoption, and state fixed effects for cross-state differences. The estimated effects are consistent as we build up to a more saturated specification which includes hospital fixed effects and hospital characteristic controls in Column (3). The pattern is also consistent when we consider a hospital system rather than an individual hospital in Column (4).

The main similarity between Table 2, which studies testing rates, and Table 8, which studies genetic testing facility adoption, is that the estimated effect of genetic consent laws is negative and significant. Quantitatively, the estimated effect of consent laws is to decrease availability of genetic testing at hospital systems by 1.6%, which is about a 10% drop relative to the average availability. The same laws were found in Table 2 to decrease genetic testing by 0.45%, which is 83% lower than the sample mean rate. This is consistent with lower availability of genetic testing at local hospitals being part of the mechanism for the decrease in testing rates that we observe among consumers when such a law is present. This lower availability may reflect additional compliance costs for hospitals considering offering testing services or lower anticipated demand when consent rules are in place. The estimate for non-genetic health privacy laws is positive for both testing and availability and the anti-discrimination laws had no significant effect on either outcome.

The main difference between Tables 2 and 8 is that positive and significant effects of laws that give control over redisclosure are not present for testing availability. One possible explanation is that supply of genetic testing (measured by number of hospitals offering the service) does not increase in response to the redisclosure laws because, by preventing resale

Table 8: Genetic Testing Availability

	(1) Genetic Hospital b/se	(2) Genetic Hospital b/se	(3) Genetic Hospital b/se	(4) Genetic System b/se
Genetic Consent Law	-0.013***	-0.0093**	-0.0070*	-0.016***
	(0.0048)	(0.0036)	(0.0037)	(0.0047)
Genetic Anti-Discrimination Law	0.014	0.025	0.024	0.031
	(0.014)	(0.017)	(0.017)	(0.027)
Genetic Redisclosure Law	0.00030	-0.0017	-0.0051	-0.0029
	(0.0072)	(0.0079)	(0.0081)	(0.016)
Health Privacy Disclosure Law	0.038***	0.045***	0.042***	0.059***
	(0.0055)	(0.0040)	(0.0038)	(0.0043)
Beds (00)			0.026***	0.019**
			(0.0057)	(0.0082)
Inpatient Days (000)			-0.000078	0.00023
			(0.00018)	(0.00026)
Medicare Share Inpatient			0.000025	0.00027**
			(0.000079)	(0.00013)
Medicaid Share Inpatient			0.00016	0.00020
			(0.00011)	(0.00016)
PPO			0.0093*	0.015***
			(0.0049)	(0.0057)
HMO			-0.00078	0.012*
			(0.0050)	(0.0071)
State Fixed Effects	Yes	No	No	No
Hospital Fixed Effects	No	Yes	Yes	Yes
Year Fixed Effects	Yes	Yes	Yes	Yes
Observations	36717	36717	36717	36717
Log-Likelihood	-7671.9	20781.2	20832.4	15130.5

OLS estimates with hospital fixed effects. Each observation is a hospital-year between 2003 and 2010. Dependent variable is decision to have genetic testing facility, either at the hospital (in the first three columns) or within the same hospital system (last column). Robust standard errors clustered at the state level. * $p < 0.10$, ** $p < 0.05$, *** $p < 0.01$

or redisclosure of test results, those laws reduce the value to hospitals of offering genetic tests. This indicates that greater availability is not a mechanism for the positive effect we observe for consumers who are contemplating genetic testing. Instead, it seems to come directly from the reassurance that such data ownership laws give to consumers.

4 Implications

This paper explores how state genetic privacy laws affect the diffusion of personalized medicine, using the case of genetic testing for predispositions for certain types of cancer.

State genetic privacy laws take three alternative approaches to protecting patient privacy: (1) Requiring informed consent on the part of the individual; (2) Restricting discriminatory usage of genetic data by employers, health care providers or insurance companies, including providers of long-term care or life insurance; or (3) Limiting redisclosure without the consent of the individual or defining genetic data as the 'property' of the individual.

We find empirically that an approach that gives users control over redisclosure encourages the spread of genetic testing, whereas an approach of informed consent deters individuals from obtaining genetic tests. We also find that there is little effect, either positive or negative, from regulation that prevents discriminatory use of this data.

These findings are important, partly because the spread of personalized medicine which is based on genetic testing has the potential to revolutionize healthcare. They are also important because there is the possibility that these results can help illuminate desirable features of privacy protection in different arenas than genetics, such as online data, financial data or health data more broadly. Our finding that non-genetic health privacy laws that limit redisclosure are associated with more genetic testing and HIV testing provides additional support for this interpretation. Our results in general appear to support privacy regimes that focus on establishing rules of data ownership rather than merely informing on the consumer how their data will be used and focusing on obtaining upfront consent. It also suggests that there are only weak effects from privacy regimes that focus on restricting usage of data. Strikingly, it is this least effective form of privacy protection that has been the focus of EU, OECD and US lawmaking over privacy.

One potential limitation of our findings is our heavy focus on early adopters of genetic testing and their response to early genetic privacy regulations. Although the mapping of the human genome and the identification of millions of mutations has already advanced science, the full potential of the genetic revolution for medical care has not yet been realized. However, at the same time, the progress of genetic science will also increase the risks to

individuals stemming from damaging uses of genetic information and so our results reflect considerable uncertainty over how these technologies and corresponding privacy concerns will develop. In particular, it is not clear how our results apply to new direct-to-consumer genetic testing services. These limitations are in addition to the normal caveats that apply to any study that uses variation in state laws to identify the effect of interest. Notwithstanding these limitations, we believe that this study provides a useful first attempt to understand how different types of privacy regulations affect the diffusion of technologies that create very sensitive data.

References

Armstrong, K., B. Weber, G. FitzGerald, J. C. Hershey, M. V. Pauly, J. Lemaire, K. Subramanian, and D. A. Asch (2003). Life insurance and breast cancer risk assessment: Adverse selection, genetic testing decisions, and discrimination. *American Journal of Medical Genetics Part A 120*(3), 359–364.

Baker, L. C. (2001, May). Managed care and technology adoption in health care: evidence from magnetic resonance imaging. *Journal of Health Economics 20*(3), 395–421.

Baker, L. C. and C. S. Phibbs (2002, Autumn). Managed care, technology adoption, and health care: The adoption of neonatal intensive care. *RAND Journal of Economics 33*(3), 524–548.

Berry, R. M. (1997). The genetic revolution and the physician's duty of confidentiality. *Journal of Legal Medicine 18*(4), 401–441. PMID: 9433035.

Ciliberto, F. (2006, March). Does Organizational Form Affect Investment Decisions? *Journal of Industrial Economics 54*(1), 63–93.

Gardner, E. (2014, Aug 1). Gene swipe: Few dna labs know whether chromosomes are yours or if you stole them. *ABA Journal*.

Goldfarb, A. and C. Tucker (2011). Privacy regulation and online advertising. *Management Science 57*(1), 57–71.

Goldfarb, A. and C. Tucker (2012a). Privacy and innovation. *Innovation Policy and the Economy 12*(1), 65 – 90.

Goldfarb, A. and C. Tucker (2012b). Shifts in privacy concerns. *American Economic Review: Papers and Proceedings 102*(3), 349–53.

Gostin, L. (1991). Genetic discrimination: the use of genetically based diagnostic and prognostic tests by employers and insurers. *American Journal of Law & Medicine 17*, 109.

Green, R. C. and G. J. Annas (2008). The genetic privacy of presidential candidates. *New England Journal of Medicine 359*(21), 2192–2193. PMID: 19020322.

Hartmann, L. C., T. A. Sellers, D. J. Schaid, T. S. Frank, C. L. Soderberg, D. L. Sitta, M. H. Frost, C. S. Grant, J. H. Donohue, J. E. Woods, S. K. McDonnell, C. W. Vockley, A. Deffenbaugh, F. J. Couch, and R. B. Jenkins (2001). Efficacy of bilateral prophylactic mastectomy in brca1 and brca2 gene mutation carriers. *Journal of the National Cancer Institute 93*(21), 1633–1637.

Jolls, C. (2007). Employment law. In A. M. Polinsky and S. Shavell (Eds.), *Handbook of Law and Economics* (1 ed.), Volume 2, Chapter 17, pp. 1349–1386. Elsevier.

Komarova, T., D. Nekipelov, and E. Yakovlev (2013). Estimation of treatment effects from combined data: Identification versus data security. In *Economics of Digitization*. University of Chicago Press.

McEwen, J. E., K. McCarty, and P. R. Reilly (1993). A survey of medical directors of life insurance companies concerning use of genetic information. *American Journal of Human Genetics 53*(1), 33.

McEwen, J. E. and P. R. Reilly (1992). State legislative efforts to regulate use and potential misuse of genetic information. *American Journal of Human Genetics 51*(3), 637.

Miller, A. R. and C. Tucker (2009). Privacy Protection and Technology Diffusion: The Case of Electronic Medical Records. *Management Science 55*(7), 1077–1093.

Miller, A. R. and C. E. Tucker (2011a, April). Can health care information technology save babies? *Journal of Political Economy 119*(2), 289–324.

Miller, A. R. and C. E. Tucker (2011b). Encryption and the loss of patient data. *Journal of Policy Analysis and Management 30*(3), 534–556.

Natowicz, M. R., J. K. Alper, and J. S. Alper (1992). Genetic discrimination and the law. *American Journal of Human Genetics 50*(3), 465.

Oster, E., I. Shoulson, and E. Dorsey (2013). Optimal expectations and limited medical testing: Evidence from Huntington disease. *American Economic Review 103*(2), 804–830.

Oster, E., I. Shoulson, K. Quaid, and E. R. Dorsey (2010). Genetic adverse selection: Evidence from long-term care insurance and Huntington disease. *Journal of Public Economics 94*(11-12), 1041 – 1050.

Ostrer, H., W. Allen, L. A. Crandall, R. E. Moseley, M. A. Dewar, D. Nye, and S. McCrary (1993). Insurance and genetic testing: Where are we now? *American Journal of Human Genetics 52*(3), 565.

Pritts, J., P. J. White, J. Daniel, and S. Posnack (2009). *Privacy and Security Solutions for Interoperable Health Information Exchange: Report on State Law Requirements for Patient Permission to Disclose Health Information*. Agency for Healthcare Research and Quality.

Savitz, J. B. and R. S. Ramesar (2004). Genetic variants implicated in personality: a review of the more promising candidates. *American Journal of Medical Genetics Part B: Neuropsychiatric Genetics 131*(1), 20–32.

Strohmenger, R. and A. Wambach (2000). Adverse selection and categorical discrimination in the health insurance markets: the effects of genetic tests. *Journal of Health Economics 19*(2), 197–218.

Tabarrok, A. (1994, March). Genetic testing: An economic and contractarian analysis. *Journal of Health Economics 13*(1), 75–91.

Vorhaus, D. (2011, Aug 12). Surreptitious genetic testing: A new bill in texas and the iowa straw poll. *Genomics Law Report*.

Yesley, M. S. (1998). Protecting genetic difference. *Berkeley Technology Law Journal 13*, 653.

Zick, C. D., C. J. Mathews, J. S. Roberts, R. Cook-Deegan, R. J. Pokorski, and R. C. Green (2005). Genetic testing for Alzheimer's disease and its impact on insurance purchasing behavior. *Health Affairs 24*(2), 483–490.

Zick, C. D., K. R. Smith, R. N. Mayer, and J. R. Botkin (2000). Genetic testing, adverse selection, and the demand for life insurance. *American Journal of Medical Genetics 93*(1), 29–39.

Table A-1: Genetic Privacy Laws and Latent Demand for Genetic Privacy

	Consent Law		Anti-Discrimination Law		Redisclosure Law	
	(1)	(2)	(3)	(4)	(5)	(6)
GINA Filed Per Pop.	-0.021		0.0016		0.032	
	(0.024)		(0.021)		(0.028)	
GINA Resolved Per Pop.		-0.029		-0.000039		0.015
		(0.027)		(0.024)		(0.032)
Constant	0.29***	0.29***	0.78***	0.78***	0.29***	0.35***
	(0.085)	(0.079)	(0.076)	(0.070)	(0.10)	(0.094)
Observations	51	51	51	51	51	51
Log-Likelihood	-21.8	-21.6	-16.1	-16.1	-30.1	-30.6

OLS estimates. State level unit of observation. Dependent variables are the share of years between 1998 and 2008 in which the state had in place a genetic privacy law of each type. Explanatory variables are the total numbers of genetic discrimination cases filed or resolved by the EEOC between 2010 and 2012, scaled to state population. * $p < 0.10$, ** $p < 0.05$, *** $p < 0.01$

Table A-2: Genetic Testing Availability and State Laws: Summary Statistics

	(1)		
	Mean	Std. Dev.	Obs.
Genetic Hospital	0.11	0.31	36717
Genetic System	0.16	0.36	36717
Genetic Consent Law	0.23	0.42	36717
Genetic Anti-Discrimination Law	0.89	0.31	36717
Genetic Redisclosure Law	0.41	0.49	36717
Health Privacy Disclosure Law	0.86	0.35	36717
Beds (00)	1.63	1.83	36717
Inpatient Days (000)	40.2	52.2	36717
Medicare Share Inpatient	48.3	22.9	36717
Medicaid Share Inpatient	18.8	18.5	36717
PPO	0.73	0.44	36717
HMO	0.62	0.49	36717

Hospital level information from the AHA Annual Survey (2003 – 2010). Privacy laws described in the text.