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Better Patient Privacy Protection with Better Patient Empowerment about Consent in Health Information Exchanges

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ABSTRACT

Since HIPAA laws have permitted broad discretion to Health Information Exchange (HIE) providers, HIEs have configured the patient healthcare consent process to privilege all providers who sign up with the Health Information Exchange with patient health information (PHI) on all consenting patients. This in a sense violates the security principle of “least privilege”. The onus of denying broad based general access for a consenting patient, now resides with the patient. The notion of making the information available to all physicians at all times because they are part of an exchange is not the best practice. Patients empowered with the right information may choose to deny access to their medical records while seeking a second opinion. This research investigates the following questions: How does a more holistic education as opposed to a one-sided message impact patient consent behavior? How does the messaging framework impact the intention to consent under different sharing settings? Utilizing an experimental survey, our results show that the binary setting (share all PHI with all providers) was the least favorable among all participants, while the customized setting was the most favorable.

Keywords: Information Privacy, Health Information Exchange, Information Sharing, HIE, HIPAA

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INTRODUCTION

Does educating patients about the pros and cons of current Health Information Exchange (HIE) consent process empower patients to provide and revoke access more dynamically to better protect their privacy? Utilizing an experimental survey consisting of 309 participants this paper attempts to answer that question.

HIEs are multisided platforms with many participating sides: patients, various types of providers such as hospitals, primary care physicians, lab tests, other providers, etc. (Kuperman, 2011). Typically providers port patient medical records to exchanges or their edge servers for other physicians to access when needed. The idea being the entire patient history will be available to any physician treating the patient. Patients often see a variety of physicians for the different ailments and the idea of sharing allows physicians to understand the patient medical history prior to delivery of care. The benefits stemming from such a practice is the avoidance of duplicate tests when possible and the availability of the record itself. This potentially could lead to greater practice efficiency and lower costs for payers (insurance companies) who would not have to pay for duplication. It also ensures that patients do not receive prescriptions that interact with other prescription drugs they are taking. This leads to better patient safety. As structured, the parties that benefit the most are the payers (insurance companies) and physicians in terms of cost and practice efficiencies. Patients also benefit but not necessarily by lower cost but by the availability of their medical history by the attending provider.

Ambulatory Care practices have not readily adopted HIE access for a variety of reasons. Health Information Exchanges cannot share patients' PHI without getting consent from the patients (Tripathi, Delano, Lund, & Rudolph, 2009). The survival of exchanges is based on physician adoption. Physician adoption is better if a greater number of patients consent to sharing information. Therefore, healthcare providers and exchanges have been exposing patients to only the benefits of sharing their PHI through HIE. Massachusetts eHealth Collaborative, MaeHC, has managed to persuade 90% of 500,000 of

patients to share their health information electronically (Tripathi et al., 2009). However, consent might imply experiencing negative outcome such as loss of privacy and information. Does a podiatrist need access to a patient's sexual ailments? From a patient perspective, sharing or giving consent to share health information is not optimal under all circumstances. For example, while seeking a second opinion, it may be advisable not to give consent to the second physician providing the second opinion to prevent his decision from being biased by the opinion of the first physician. Also, there could also be a loss of privacy that can result due to sharing of private information indiscriminately especially when there is a breach of security and the private health information is available publicly. According to the Department of Health and Human Services, the health data of 120 million people has been breached since 2009.

There is a need to obfuscate certain information from certain physicians. A patient may not want to disclose information about his/her visits and treatments relating to sexually transmitted diseases, minor mental problems, etc. to his/her primary care physician or to other physicians providing care for an entirely different purpose. More importantly, the HIPAA privacy rule grants covered healthcare providers the right to tailor patients' consent forms, material, procedures, and options. [See 45 C.F.R. § 164.506(b)]. As a result, most healthcare providers do not grant patients any level of granularity to control what information to share or with whom. Therefore, we are interested to investigate how the patients' intention to share their health information changes when provided with flexible sharing options as opposed to rigid sharing options. We also investigate how patients' intentions to share PHI electronically through HIE change when exposed to two different types of educational messages: a one-sided message including only possible health and economic benefits of sharing health information, and a two-sided message including both possible benefits and drawbacks of sharing health information.

RESEARCH BACKGROUND

Most of the current research is focused on investigating the barriers of adoptions for healthcare providers, and finding ways to ease the process and enhance the experiences. Although, the patient is presumed the central beneficial of the technology, limited literature has investigated the patients' side of the equation. In this section we highlight some of the literature in the information sharing in health information systems (see Table-1).

Information Sharing in Health Information Systems

Reference	Main Objective	Main Findings	Sample
(Caine & Hanania, 2012)	To investigate peoples' willingness to share all of their health information.	All patients want to share partial information with select providers. Type of information to be shared and providers to share the information with are different across patients.	30 participants
(Tripathi et al., 2009)	To highlight the significance of engaging patients and reaching out to patients when Massachusetts eHealth Collaborative conducted consent.	The material, policies and procedures developed resulted in 90% consent rate.	Three communities, 500,000 patients
(Anderson & Agarwal, 2011)	To investigate the circumstances under which patients are willing to disclose personal health information and permit digitalization	Negative emotions influence individual's willingness to disclose PHI	1,089 participants
(Angst & Agarwal, 2009)	To investigate ways to persuade patients to change attitude and intention toward consent even under privacy concerns.	Positive arguments can persuade patients to consent even under the presence of privacy concerns	366 participants
(Adams, Budden, Hoare, & Sanderson, 2004)	To highlight the lessons learned from the pilot project of implementing Hampshire HER: issues of data protection and consent	Most respondents wouldn't want restriction on the shared medical.	2,000 participants
(O'Donnell et al., 2011)	To investigate consumers' attitude toward HIE and factors influencing attitude.	Majority of respondents supported use of HIE. Suggests outreaching to patients and clarify privacy policies.	170 participants
(Sibona, Walczak, Brickey, & Parthasarathy, 2011)	To investigate patients' perceptions of EMR	Patients who have used EMR believe that EMR benefits are operational but don't improve health outcomes, they also don't want more control over their information.	242 participants
(Teixeira, Gordon, Camhi, & Bakken, 2011)	To evaluate HIV patients' attitude toward sharing their Health information electronically.	Attitude towards sharing health information is positively associated with trust and respect of clinicians.	93 participants

(Grande, Mitra, Shah, Wan, & Asch, 2013)	To evaluate patients' preference toward sharing their electronic health information for secondary purposes.	The sensitivity of medical information is not a significant influence. The purpose of the use NOT the user of information is the most important decisive factor for sharing health information.	3,336 participants
(Weitzman, Kelemen, Kaci, & Mandl, 2012)	To investigate patients' willingness to share personal health information to improve public health.	Sharing sexually transmitted disease with an outside provider was not preferred. Families of pediatric patients are mostly willing to share health information to improve health outcomes.	261 participants
(Zulman et al., 2011)	To investigate patients interest in sharing personal health information among users of the U.S. department of veteran affairs.	Sharing was dependent on the type of information being shared. Sharing of prescriptions and lab test results was preferred.	18,471 participants
(Perera, Holbrook, Thabane, Foster, & Willison, 2011)	To examine patients and physicians perceived benefits in sharing health information for secondary purposes.	Patients and physician are concerned with the outsiders accessing health information even without personal identifiers. Physicians see more overall benefits than patients do.	490 participants
(Weitzman, Kaci, & Mandl, 2010)	To examine patients' willingness to share their personal health records for health research.	Willingness to share is positively influenced by experiencing health emergency. Anonymity increases the likelihood of sharing health information for public health research.	151 participants
(Dhopesw arkar, Kern, O'Donnell, Edwards, & Kaushal, 2012)	To examine patients' privacy and security concerns associated with sharing information in HIE.	Sharing and concerns were associated with who access the information. Patients' trust doctors to view health information even without permission but don't trust government officials and employers.	170 participants
Table-1: Information Sharing in Health Information Systems			

Privacy concerns and trust are the main barriers behind denying sharing. In general, there is a positive attitude towards HIEs, however the attitude does not translate into sharing intention or behavior. These findings trigger the need for a more flexible consent mechanism which we try to capture in our experiment. To capture the need for a more flexible consent mechanism we classify intention to share PHI (our dependent variable) into different sharing settings.

Privacy in Health Information Sharing:

In this section we review privacy in the health information systems stream. Prior research have emphasized privacy as one of the main concerns and barriers behind non-disclosure of medical information (Anderson & Agarwal, 2011; Angst & Agarwal, 2009; Simon, Evans, Benjamin, Delano,

& Bates, 2009). A potential drawback in sharing information in HIE is the risk of patient privacy invasion and information security violations, which is an increasing concern due to the increasing amount of health information exchanged electronically. Healthcare providers are driven by increased participation and systemic cost savings irrespective of benefits to individual patients. HIE is a new technology and the risk of information breaches and privacy issues are not understood by the patients yet, especially when there is lack of education. Moreover, when security breaches occur, patients are not compensated for their losses which makes sharing of high privacy and security risk. Patients privacy concerns are impacting the growth of HIE (Yasnoff, Sweeney, & Shortliffe, 2013) therefore there is a need to investigate other factors that impact sharing decisions and overcome privacy concerns. In Table-2, we highlight some of the main literature in this context.

Reference	Main Objective	Main Findings	Sample
(Patel et al., 2012)	To investigate consumers attitude toward HIE and PHR	Majority of respondents supported use of HIE and PHR. Enhancing HIE/PHR rate can be achieved by addressing privacy and security concerns, establishing health benefits, and reaching out less educated consumers.	117 participants
(Patel et al., 2011)	To investigate low-income and ethnically diverse consumers' attitude towards HIE and PHR.	Consumers have concern over the privacy and security of their information. Attitude toward sharing medical information is positive for those who believed that HIE would improve quality of care.	214 participants
(Simon et al., 2009)	To investigate patients' views about sharing of electronic health information	Main concerns were 1- privacy and security. 2- The possible benefit to an individual's health. 3- The need for more information about the consent process.	62 participants (focus-group)
(Bansal, Zahedi, & Gefen, 2010)	To investigate the impact of Personality traits, health status, privacy concerns, and information sensitivity disclosing health information online	Health status, privacy concerns, information sensitivity, and some personality traits play roles in the decision to disclose health information online.	367 students
(Hassol et al., 2004)	To investigate patients' perception toward the use of EHR and web messaging.	Patients are positive about the use of EHR and web messaging. Most patients were not concerned about the privacy of their information.	4,282 (Geisinger Health System)
(Li, Gupta, Zhang, & Sarathy, 2012)	To investigate the impact of privacy concerns, trust and perceived benefits in individual's intention to use PHR.	The perceived benefits and privacy concerns of Personal Health Records (PHR) are the main determining factors to patients in order to adopt PHR.	192 students

(Dimitropoulos, Patel, Scheffler, & Posnack, 2011)	To investigate public attitude toward HIE.	Majority of respondents are concerned with privacy and the security of information. Over half of the respondents want to tailor their information sharing. Most respondents agree on some benefits of HIE.	1,847 participants
(Ancker, Edwards, Miller, & Kaushal, 2012)	To evaluate consumers' perceptions of HIE in New York state.	Majority of respondents supported use of HIE, had privacy concerns and thought that consent shouldn't be needed in emergency situations. Suggests outreaching to patients and clarify privacy policies.	800 participants
(Platt & Kardia, 2015)	To investigate the characteristics that predict trust in healthcare information systems that include all healthcare stakeholders.	Perceived benefits for the public are positively associated with trust but privacy concerns are negatively associated with trust.	447 participants
(Wen, Kreps, Zhu, & Miller, 2010)	To investigate patients attitudes towards use HIE and PHR.	In general HIE and PHRs are perceived beneficial but there are concerns for privacy and security of the information.	7,674 participants (2007 HINTS data)
Table-2: Privacy in Health Information Sharing			

These findings suggest that there is a need for a better educational and communication messages and patients need to be part of the decision making by controlling their health information. In this experiment, we expose patients to different educational messages and allow them to control their health information. The findings of our study can benefit healthcare providers and policy makers by giving them insights on how they can address privacy concerns, improve consent's mechanisms to benefit patients. The findings also indicate that privacy concerns and trust are major factors influencing intention to share. We try to investigate if the impacts of those factors diminish under more flexible consent options. The gap in the literature is that consent was presumed beneficial and patients were not exposed to any drawbacks. To our knowledge there is no paper that investigates the impact of message framing on consent behavior of patients.

Message Framing: Investigating the effect of persuasive messages is widely used specially in medical field (O'Keefe & Jensen, 2007). There are several theories and methods when it comes to framing persuasive messaging. Perhaps one of the most famous theories is prospect theory (Kahneman & Tversky, 1979) where arguments are framed either in terms of gains or losses.

Messages can be expanded to promote pleasure, promote pain, prevent pleasure or prevent pain.

Similar to the previous approaches Rathman & Salovey (1997) identified four types of framing which are a combination of Attain/Not Attain and Desirable/Undesirable. The Fuzzy-Trace Theory (Reyna & Brainerd, 1991, 1995) expands on the Prospect Theory by introducing multiple layers of certainty under each of the gain and loss framing. This means a gain or a loss message can be of certain outcome, high probability, low probability, or unsure outcome.

However, the drawback of those framing theories is that they expose the recipient to a one-sided message regardless of the content and context. Meaning, the different message contain the same information but are framed in different ways (i.e. risk vs gain). We want to investigate the difference between the impact of a one-sided message and a two sided message on intention to share PHI electronically. Drawbacks and benefits are not equivalent and therefore the framing theories are not applicable. Therefore, we adopted the Inoculation Theory (Szybillo & Heslin, 1973) which is used in marketing research to investigate the impact of one-sided vs a two-sided message in various contexts (Etgar & Goodwin, 1982).

STUDY DESIGN

We are interested in investigating changes in patients' intentions towards sharing health information when exposed to different settings of sharing. This research investigates the following research question: How does a more holistic (two-sided message) education as opposed to a one-sided message impact patient consent behavior?

This study can help healthcare policy makers understand the structure of more effective messages that will empower patients with knowledge about what consent might imply. This will guide individuals to make the right sharing decision for their own individual characteristics and level of privacy concern. Denying consent is ideal in some cases in which it will result in more benefits for the patients. These

are situations where patients don't need to share irrelevant sensitive medical history with specific physicians as this often leads to privacy issues and negative attitude towards sharing.

Procedure: We administered the survey through Amazon Mechanical Turk (MTurk) which is an online survey administration platform that allows for efficient collection of pre-test and post-test data from participants. MTurk is reliable, valid and effective data collection approach (Steelman, Hammer, & Limayem, 2014). MTurk is as reliable as traditional pools (Ayyagari, Grover, & Purvis, 2011). Also, ng a video message. We assume that everyone is a patient and that sharing PHI via HIE is valid for everyone that goes to any healthcare provider. Online surveys have been used in top Information Systems journals in the context of sharing health information electronically (Angst & Agarwal, 2009).

We surveyed 309 people. Incentive is provided to participants through Amazon. Online surveys have an advantage over paper surveys in reducing response change bias under experimental design (Meier, 2013). With a paper survey, people can always go back and check their pre-intervention answers, then intentionally manipulate their answers to show or not show change in responses. A hidden timer was used in the video section. Participants who didn't watch the entire video where excluded. Participants were asked questions about their privacy concerns, trust in the systems, and their intention to share their PHI via HIE (see table-4). Then, we randomly assigned participants to one of three groups: 1. One-Sided Message - participants in this group watched to a video message that only highlights the benefits of sharing PHI via HIEs. 2. Two-Sided Message - participants watched a video message that highlights both possible benefits and drawbacks of sharing PHI via HIE. 3. Placebo: participants watched a video message that is irrelevant to sharing PHI.

We investigated the changes in intention towards sharing health information after being exposed to one-sided or two-sided messages. This allows us to capture not only the changes in the response variable but also how the impact of the messages on the intention to share health information change

under different sharing settings (share all/by type of information/ by provider/ by type of information and by provider).

Messages: The drawbacks message includes privacy risk, loss of information control, and biased second opinion. Benefits message includes less medical errors, faster medical care, and less redundant tests. The messages were maintained to have similar characteristics: similar number of words, complexity factor level, readability level (fog index), and sentiment level (see table-3).

Measure	Benefits	Drawbacks
Complexity factor (Lexical Density) :	51 %	52%
Readability (Gunning-Fog Index) : (6-easy 20-hard)	13.7	12.8
Document Sentiment	0.088424	-0.017
Table-3: Message Characteristics		

Variables Definitions: Dependent Variable - Intention: Patients’ intentions to consent was measured under four different sharing settings: 1. Binary options: patients either share all of their PHI with all providers or share nothing. 2. By type of information: patients can select specific PHI to be shared. However, all healthcare providers will be able to access the shared information. 3. By provider: patients can choose select healthcare providers to access all of their PHI. 4. Customized: patients can select specific personal health information to be shared with specific health care providers. Definitions and scales for the independent and dependent variables are defined in table highlighted in table-4.

Construct	Definition	Source
Trust	The extent to which a patient has trust in the HIE system	(Tax, Brown, & Chandrashekar, 1998)
Concern for Information Privacy (CFIP)	Individual’s views about information privacy linked to the use of personal information in a healthcare situation.	(Smith, Milberg, & Burke, 1996)
Intention to consent	Intention to consent to sharing personal health information in HIE	(Malhotra, Kim, & Agarwal, 2004)
	(Measured four times under the four settings described in variable definition section).	
Table-4 : Variables definitions		

ANALYSIS AND RESULTS

We ran a pilot test through Amazon Mechanical Turk where we collected 309 complete and valid responses. 101 participants were exposed to a one-sided message video, 105 participants were exposed to a two-sided video message and 103 were exposed to a placebo video. We used SAS version 9.4 for these analyses. We applied difference-in-difference technique to measure the difference between the treatment group and the placebo group (the impact of the educational video message on the change in intention to consent). Table-5 reports the results of the test.

Dependent Variable = Intention to consent Comparison group= Placebo								
Sharing Setting	Binary		By Type of Info.		By Provider		Customized	
Group	One-Sided	Two-Sided	One-Sided	Two-Sided	One-Sided	Two-Sided	One-Sided	Two-Sided
Message	0.121	-0.066	0.246***	-0.047	0.165*	-0.059	0.142	-0.094
***= p < .01; ** = p < .05; * = p < .10								
Table-5: Impact of educational messages on change in intentions								

The results show strong impact of the one-sided messages on the change in intention to consent under the flexible sharing settings (sharing by type of information and sharing by provider while the impact under the customized setting is marginally significant). The one-sided message results no impact under the share all setting. These findings support our emphasis on enforcing more flexible consent options. The educational message is more persuading when options are flexible. Flexible options do overcome privacy and other concerns. The two-sided message, however, shows no impact under any of the four settings. An important finding is that the binary sharing setting was the least favorable among all participants, while the customized options was most favorable. This indicates that flexible consent options are desirable and will drive higher consent rates. In Table-6, we show results from pre-education measurements. Trust in HIE is positively associated with the intention to consent in all four settings. Likewise, CFIP is significant in all settings except for the binary sharing setting.

Sharing setting	All info. with all providers	By Type of Info.	By Provider	Customized
Variable	Estimate	Estimate	Estimate	Estimate
CFIP	0.000490 (0.12088)	0.30835*** (0.09926)	0.19696** (0.09059)	0.59346*** (0.09276)
Trust	0.62747*** (0.09058)	0.4225*** (0.07438)	0.58773*** (0.06789)	0.32335*** (0.06951)
Controls	Yes	Yes	Yes	Yes
R-Square	0.3578	0.2937	0.4459	0.3889
*** = p < .01; ** = p < .05; * = p < .10				
Table-6: Models and results				

According to the HIPAA a patient has the right to request a flexible sharing option but it is up to the healthcare provider to satisfy the request or enforce the (yes/no) options. Because of flexibility given to healthcare providers, flexible options are not offered. We collected data about HIPPA privacy rules, states privacy rules, and HIE consent forms in 17 states. We found that only 9.4% of the HIEs grant patients some level of granularity in controlling the people who have access to the patients’ PHI. Over 90% of HIEs in those 17 states only provide patients with two binary sharing options; either to share all health information with all providers or nothing at all. We found one HIE in all 17 states that included information addressing patients privacy concerns. The one-sided message didn’t impact patients’ intention to share under binary sharing decisions. The binary setting was the least favorable pre-message and post-message. Only the availability of flexible options helped the message to succeed in persuading participants. The consent rate for the flexible options was even higher after the one sided message. In other words, neither education nor flexible settings can drive consent alone. The existence of both help the systems to succeed.

CONCLUSION

Patients are heterogeneous; they have different levels of privacy concerns and different levels of trust and thus the consent mechanism should be designed to address these variances. Having a successful information sharing platform comes from the possible benefits of each stakeholder. Since patients

favor customized consent options, then policy makers and healthcare providers should make these options available to patients. Patients want to be have control over their privacy which can be achieved by granting them the right to choose what information to share and with who. Patients want to be involved in the decision making process, they want to be able to discuss treatment options with their physicians and contribute to the final decision (Coulter, Entwistle, & Gilbert, 1999). Giving patients the right to restrict specific information from certain people, makes patients part of the decision making process.

Educational video messages do have an impact on peoples sharing intentions. The impact is different depending on the sharing settings. If educational messages are developed to inform patients and flexible consent options are enforced we expect to have higher consent rates and more educated patients' population that make the right decision for their situation. Thus, a consent decision may also be influenced by the number of factors including the type of message but also the flexibility of available options. Privacy issues can be addressed by giving patients the right to control their privacy.

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