

Special Communication

Greater patient health information control to improve the sustainability of health information exchanges

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ABSTRACT

Health information exchanges (HIEs) are multisided platforms that facilitate the sharing of patient health information (PHI) between providers and payers across organizations within a region, community or hospital system. The benefits of HIEs to payers and providers include lower cost, faster services, and better health outcome. However, most HIEs have configured the patient healthcare consent process to give all providers who sign up with the exchange access to PHI for all consenting patients, leaving no control to patients in customized what information to share and with who. This research investigates the impact of granting greater control to patients in sharing their personal health information on consent rates and making them active participants in the HIEs system. This research utilizes a randomized experimental survey design study. The study uses responses from 388 participants and structural equation modeling (SEM) to test the conceptual model. The main findings of this research include that patients consent rate increases significantly when greater control in sharing PHI is offered to the patient. In addition, greater control reduces the negative impact of privacy concern on the intention to consent. Similarly, trust in healthcare professionals leads to higher consent when greater control is offered to the patient. Thus, greater control empowers the role of trust in engaging patients and sustaining HIEs. The paper makes a theoretical contribution to research by extending the unified theory of acceptance and use of technology (UTAUT) model. The findings impact practice by providing insights that will help sustain HIEs.

1. Introduction

Health information exchanges (HIEs) are multisided platforms that facilitate the sharing of patient health information (PHI) between many participating sides: patients and various types of providers, such as hospitals, primary care physicians, and lab test providers [1]. Typically, providers import patient medical records to exchanges or their edge servers for other physicians to access when needed. Patients often see a variety of physicians for the different ailments at different points in time over their lifespan, and this makes their medical records highly fragmented. HIEs allow for integration of a patient's record from multiple sources across the time horizon. This makes the entire patient history available to any physician treating the patient prior to the delivery of care. The benefits stemming from such a practice are 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 (i.e., insurance companies) who now do not have to pay for duplication. Providers also benefit by having the entire patient information available for making decisions about patients. This helps providers make quality decisions about the patients' conditions

which as a result, reduces medical errors and improves health outcomes. While the financial benefits of provider practices are not well established, federal incentives and penalties stemming from meaningful use initiatives provided the motivation for greater participation. Availability of patient records to providers also ensures that patients do not receive prescriptions that interact with other prescription drugs they are taking. This leads to better patient safety.

As HIEs are structured, the parties that benefit the most are the payers (i.e., insurance companies) and, to an extent, physicians, regarding cost and practice efficiencies. Patients do benefit not necessarily by lower cost, as such savings are often not passed on to patients, but by the availability of their medical history to the attending provider. For example, when a patient shares his or her PHI with providers and as a result, unnecessary tests are avoided, the insurance company saves the cost of the eliminated redundant tests. However, the insurance premium for that patient does not decrease because of savings that the insurance company incurred when the patient shares his or her PHI. HIEs benefit payers and indirectly providers, on occasion. HIEs cannot share patients' PHI with physicians who are part of the health exchange without getting consent from the patients [2].

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The survival of exchanges is therefore linked to provider adoption of HIE (become a participating member of the HIE network). Physician adoption is better if a greater number of patients consent to sharing information; however, consent rate is still not up to the expectations [3]. Research on improving the adoption of HIEs is currently focused on the adoption of providers [4]. Further, most patients are passive participants of exchanges even when they opt to share, as they are only informed of their benefits that stem from consenting to share their PHI.

However, if patients become active participants in HIEs, this ownership and participation relationship could change the dynamics regarding sustainability of HIEs. Further, it could also open up avenues for revenue generation and a wide variety of specialized services that HIEs can offer in the future. This is especially true as HIEs of the future will likely contain the medical records of other family members, and these can be harnessed for better preventive care, among other things. For example, in the future, patients may be able to choose to share their health information among family members. This could help healthcare providers make even better decisions when the entire family history is available. A mechanism for HIEs to engage patients is to offer more control to the patients who want to share their personal health information.

The privacy rule of the Health Insurance Portability and Accountability Act (HIPAA) grants covered healthcare providers as HIEs the right to tailor patients' consent forms, material, procedures, and options as appropriate¹. In addition, state privacy laws vary. It is this provision—that is, the broad level at which the regulations of the HIPAA have been defined with regard to data in HIEs—that has led to implementations by HIEs that violate the principle of least privilege. Most healthcare providers do not grant patients any level of granularity in controlling which information they share or with whom. This paper studies the impact of providing patients greater control in managing the sharing of their medical records on consent. This paper attempts to answer two main research questions: Will greater control in PHI sharing yield higher HIEs consent? How does greater control in PHI sharing change the relationship between independent variables (e.g., privacy concerns and health concerns) and intention to consent? Using a randomized experimental survey design, this paper tries to answer these questions. This research contributes to theory by extending the unified theory of acceptance and use of technology (UTAUT) model in the context of sharing health information electronically. This paper also provides practical insights on how to sustain HIEs and increase consent rate by offering greater control in PHI sharing to patients.

2. Background

2.1. Literature review

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 [5]. Although the patient is the central beneficiary of the technology in terms of improved health outcomes and reduced medical errors, limited literature has investigated the patients' side of the equation [4]. This section highlights some of the literature in the information sharing in health information systems. In general, HIEs are positively considered. However, this attitude does not translate into sharing intention or behavior. Yaraghi, Sharman [6] suggest that older and female patients have a higher tendency to sharing their PHI via HIEs. Caine and Hanania [7] findings suggest that patients do not want all of their medical information shared with all possible recipients. Although in these authors' study the type of information that can be shared and the type of recipient that can access the information varied by patients, all patients agreed to partial access.

On the contrary, Adams, Budden [8] reported that the majority of

respondents would not restrict access to their shared information. Also, Hassol, Walker [9] found that most patients had a positive attitude toward the user of their information in the electronic health record (EHR) and were mostly not concerned with the privacy of their information. Likewise, Ancker, Edwards [10] indicated positive consumers' attitude towards the use of HIEs and suggested addressing security concerns. Simon, Evans [11] investigated the barriers to consent with 62 patients in a focus group. The study reports three main concerns: security concerns, lack of knowledge of possible benefit to an individual's health, and the need for more information about the consent process. Grande, Mitra [12] found that the sensitivity of the information is not a barrier for sharing. Patients focus more on how the information will be used, rather than what information is used.

Tripathi, Delano [2] highlighted the significance of reaching out to patients on the willingness of personal health information through lessons learned from The Massachusetts eHealth Collaborative (MAeHC). Angst and Agarwal [13], on the basis of a survey with 366 participants, argued that patients can be persuaded to have their information digitalized and used in the EHR. Dhopeswarkar, Kern [14] stated that patients trust physicians, but do not trust employees when it comes to having access to health information. A survey of 170 residents in New York State shows that most people want to know who viewed their information [15]. Platt and Kardia [15] suggested that perceived benefits and quality of care are positively associated with more engagement in the system.

Dimitropoulos, Patel [16] argued that most patients agree on the benefits of sharing their health information, but they want to tailor the information that is shared. Weitzman, Kelemen [17] argued that patients do not want to share information about sexually transmitted diseases with providers. Yasnoff, Sweeney [18] emphasized the need to investigate ways to overcome barriers to health information sharing and increase sharing.

Demirezen, Kumar [19] suggested that HIEs have to offer value-added services to attract more healthcare providers and sustain the systems. Yaraghi, Du [20] explored drivers of the adoption of HIEs by healthcare providers and found that HIEs have large market share, and a high number of shared patients are more likely to adopt these systems than others. Despite the vast extant of studies relating to HIEs and concerns about security, prior research did not address the issue of HIEs by providing a personal health record (PHR) system to patients. This research is important as PHRs offered to patients by HIEs could improve patient involvement and engagement with HIEs, thereby improving their sustainability.

2.2. Conceptual model development

This work adapts the UTAUT model [21] to the context of HIEs. This study investigates how privacy concerns, trust in healthcare professionals, perceived usefulness, health concerns, and social influence affect the intention to consent. It also explores how offering patients greater control in sharing their PHI impacts this relationship, as Fig. 1 shows. This paper integrates trust and privacy concerns in the UTAUT model because they have been identified as main factors affecting the use of health information technologies [22,23]. Health concern is used as a facilitating condition in the healthcare context. In addition, this research tests how the UTAUT model changes if the sharing setting in HIEs changes. The following Sections 2.2.1-2.2.6 present arguments for all hypotheses in this study.

2.2.1. Patient control over PHI sharing

The literature cites many examples of the impact of greater control on the intention to disclose private information. For instance, in 2009, Facebook added a policy that allows its users to choose the recipients of each wall post, and Cavusoglu, Phan [24] investigated the causal effect of granting Facebook users more control over which information they can share and with whom. Their findings indicate that the new policy

¹ 45C.F.R. § 164.506(b).

technology among patients.

H3a. Social influence is positively associated with the intention to consent.

H3b. More control over the mechanism of information sharing will influence the association between social influence and intention to consent.

2.2.4. Trust in healthcare professionals

Trust in healthcare professionals refers to the extent to which a patient has trust in physicians and users of the system who have access to the patients' information. Consent to sharing personal health information implies that patients give users the right to view personal information, such as lab tests, medication prescriptions, medical conditions, doctors' notes, and personal data (e.g., name and age). This includes sharing irrelevant sensitive medical history with primary care physicians providing care for an entirely different health problem. Trust in users is a major factor in the health information context [36], thus it should be included in the UTAUT in the healthcare context. Li et al. [37] argued that patients who trust in clinicians are positively associated with the attitude towards sharing personal health.

Dhopeswarkar, Kern [14] stated that patients trust physicians when it comes to having access to health information. However, most people want to know who viewed their information. For patients with HIV, trust in clinicians is associated with a positive attitude toward sharing health information [38].

H4a. Trust in healthcare professionals is positively associated with the intent to consent.

H4b. More control over the mechanism of information sharing will influence the association between trust in healthcare professionals and intention to consent.

2.2.5. Health concerns

The expression "health concerns" refers to the degree to which health concerns are part of an individual's daily lifestyle. Bulgurcu, Cavusoglu [39] suggested that people's beliefs about the consequences of a behavior have a direct influence on their intention to engage. The commonly held belief is that when a person's entire medical history is available at hand, the delivery of health can be better tailored at an individual level, resulting in better quality and timely care [40]. When patients consent to share their PHI with providers, they are expecting physicians to use this information make better decisions [27]. Thus, patients are sharing information because they are concerned about their health and want to seek a better health outcome through giving doctors the information they need to give better opinions. Therefore, the higher the health concern, the higher the individual's willingness to consent.

H5a. Health concerns are positively associated with the intention to consent.

H5b. More control over the mechanism of information sharing will influence the association between health concerns and intention to consent.

2.2.6. Perceived usefulness

The UTUAT model defined performance expectancy as the degree to which the system can help users of the system to achieve better goals [21]. In the healthcare context, patients' goals correspond to outcomes and services related to their personal health. Therefore, in this study the author defined "perceived usefulness" in the health information context as the degree to which patients believe that the system will help them achieve better health outcomes. Yaraghi [41] suggested that HIEs reduce costs, Carr, Gilman [42] argued that HIEs improve health outcomes, and Williams, Mostashari [43] emphasized that HIEs improve

the quality of service to patients. Platt and Kardia [15] suggested that perceived benefits and quality of care are positively associated with engagement in the system. Ancker, Edwards [10] used data from The Empire State Poll of adults in New York State and found that the majority of respondents believe HIEs improve the quality of care. Fontaine, Zink [44] found that improving the quality of care is a motivator for the adoption of HIEs.

H6a. Perceived usefulness is positively associated with the intention to consent.

H6b. More control over the mechanism of information sharing will influence the association between perceived usefulness and intention to consent.

3. Methods

3.1. Procedure

This research utilizes responses from 388 participants through Amazon Mechanical Turk (MTurk) which is an online survey administration platform that allows for efficient collection data from participants. Participants are recruited through Amazon Mturk and financial incentive is provided to participants who complete the survey through Amazon. Participation in the study was limited to people who reside in the United States and are at least eighteen years old. MTurk is as reliable as traditional pools [45]. An online survey has been used in top information systems journals in the context of sharing health information electronically [13]. MTurk has a reliable, valid, and effective data collection approach [46]. Participants were randomly assigned to one of two groups: (A) Binary Sharing Setting or (B) Customized Sharing Setting.

A Binary Sharing Setting represents a sharing mechanism in which a patient shares all of his/her personal health information with all participating providers or shares nothing at all. A Customized Sharing Setting is a mechanism in which a patient can choose what PHI to share and with whom.

Fig. 2 shows the procedure by which participants took the survey. The study included 388 participants in which 195 participants were randomly assigned to group A and 193 participants were randomly assigned to group B. All participants were asked the same questions regarding the antecedents, which include privacy concerns, trust in healthcare professionals, perceived usefulness, health concerns, social influence, and demographics.

3.2. Data description

At the outset, the author cleaned the data by removing all invalid responses. Of the 388 participants, about 41% were male and 59% were female. The mean age for the participants was about 39. The oldest person in the sample was 78 year old and the youngest was 19. Approximately 61% of the participants had at least one chronic disease.

3.3. Constructs

All constructs were operationalized using existing scales from previous studies. In this study, the items from the original scale were slightly modified to be suitable in the healthcare context. The questionnaire consisted of items measuring constructs in the conceptual model; the respondents scored each of these questions on a five-point Likert-type scale (1 = strongly disagree to 5 = strongly agree). The items for intention to consent and trust in healthcare professionals were adapted from Malhotra, Kim [47] work. The items for social influence were adapted from Wu [48] study. Privacy concerns construct was adapted from Dinev and Hart's [49,50] works. The items for perceived usefulness were adapted from Davis [51] research. The items for health

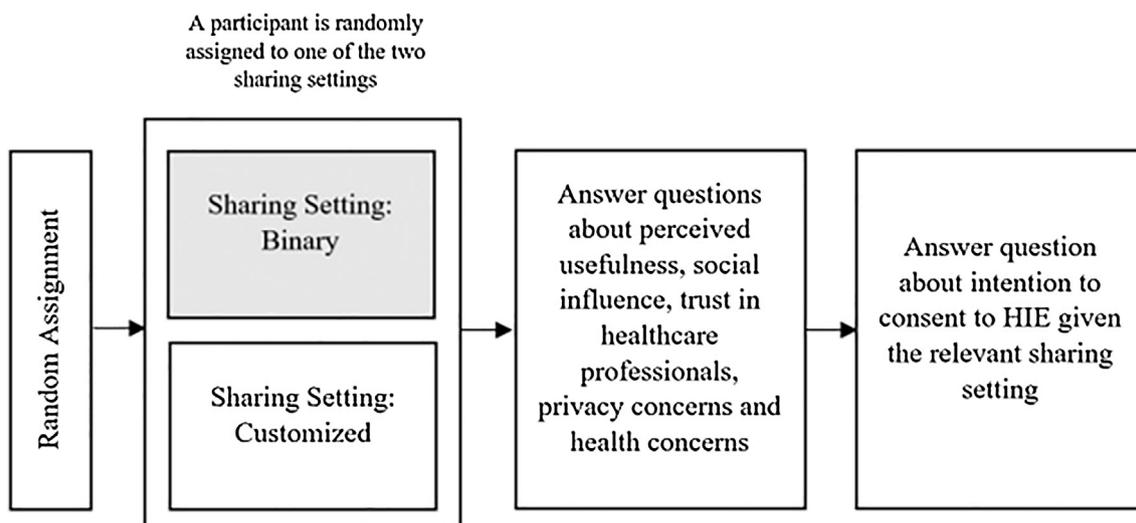


Fig. 2. Procedure.

Table 1
Constructs items.

Construct	Code	Items
Trust in health professionals	THP1	Users (such as doctors, administrators, and nurses) of HIEs ... are credible.
	THP2	are trustworthy.
	THP3	adhere to a set of principles (e.g., honesty and promise keeping) that I (the patient) find acceptable.
Privacy concerns	PC1	I am concerned about threats to the privacy of my electronically stored personal health information.
	PC2	All things considered, I believe the privacy of my electronic personal health information is seriously threatened.
	PC3	I am concerned that my electronic personal health information could be misused.
Perceived usefulness	PU1	Overall, using HIEs will be advantageous.
	PU2	The advantages of HIEs will outweigh the disadvantages.
	PU3	HIEs will be of beneficial to me.
Health concerns	HC1	I always worry about my health.
	HC2	I worry about my health more than other people worry about their health.
	HC3	My health is a concern in my life.
Social influence	SI1	People who influence my behavior would think that I should consent to HIEs.
	SI2	People who are important to me would think that I should consent to HIEs.
	SI3	People who are important to me recommend consenting to HIEs.
Intention to consent	<i>Binary Sharing Setting group:</i>	
	Sharing setting (Share everything with everyone):	
	Patients have to share all personal information with all healthcare providers or share nothing.	
	<i>Customized Sharing Setting group:</i>	
	Sharing setting (customized):	
	Patients have the right to select the type of information to share and who to share it with.	
	Under this setting, as a patient...	
	INTALL1	I am likely to consent.
	INTALL2	I will probably consent.
	INTALL3	I am willing to consent.

concerns were adapted from Jayanti and Burns’s [52] study. Control was a dummy variable (1 = group B – Customized Sharing Setting, 0 = group A – Binary Sharing Setting). Gender and number of chronic diseases were used as control variables (see Table 1).

3.4. Measurement model fit

Confirmatory factor analysis (CFA) was used to assess the validity of the measurement model. All multiitem constructs were included in the CFA that was performed using AMOS 24. The results are reported in Table 2 and shows that the CFA loadings for the constructs are very high and significant. The values of fit indices for the author’s measurement model exceeded the threshold, showing an excellent fit of this

model (X^2/DF is 1.884, root-mean-square error of approximation (RMSEA) is 0.048, comparative fit index (CFI) is 0.98, and Tucker-Lewis fit index (TLI) is 0.975). Hu and Bentler [53] reported the following threshold to represent excellent fit: $X^2/DF < 2$, RMSEA < 0.06 , CFI > 0.95 , and TLI > 0.95 .

3.5. Reliability, validity, and multicollinearity

Composite reliability and Cronbach alpha were used to establish the reliability of the constructs. The scores of composite reliability for all the constructs exceeded the threshold of 0.70 [54]. Table 2 shows the scores of composite reliability, which ranged between 0.789 and 0.968. The Cronbach alpha values were also well above the cutoff value of

Table 2
Results of the measurement model.

Variable	Item	Loading	P-value	Composite reliability
Intention to consent	INT1	0.969	< 0.001	0.968
	INT2	0.952	< 0.001	
	INT3	0.939	< 0.001	
Privacy concerns	PC1	0.782	< 0.001	0.838
	PC2	0.785	< 0.001	
	PC3	0.819	< 0.001	
Trust in health professionals	THP1	0.919	< 0.001	0.921
	THP2	0.888	< 0.001	
	THP3	0.869	< 0.001	
Perceived usefulness	PU1	0.83	< 0.001	0.88
	PU2	0.866	< 0.001	
	PU3	0.832	< 0.001	
Social influence	SI1	0.891	< 0.001	0.93
	SI2	0.938	< 0.001	
	SI3	0.878	< 0.001	
Health concerns	HC1	0.852	< 0.001	0.789
	HC2	0.785	< 0.001	
	HC3	0.584	< 0.001	
Values of fit indices of the measurement model	RMSEA	0.048	TLI	0.975
	CFI	0.98	X ² /DF	1.884

point 0.70 [55]. Table 3 reports the Cronbach α values, which ranged between 0.78 and 0.97. These results establish the reliability of all multiitem constructs in the study.

Convergent validity is assessed by calculating the average variance extracted (AVE), where each indicator is related to only one construct. The AVE values for all constructs exceeded 0.5, which is the necessary threshold, and thus established convergent validity for the construct [56] (see Table 4). In addition, the exploratory factor analysis (EFA) showed strong loading on the items that belonged to the same questions under their relevant factor. Discriminant validity was established as the AVE values for any two constructs exceeded the squared construct intercorrelation for each pair [56]. Table 5 shows the AVE scores and the correlation matrix. In addition, the EFA results show that items of the same construct loaded low on other factors and high on their relevant factor, and thus established discriminant validity (see Table 3).

In order to test for multicollinearity, the variable inflation factor

Table 3
Exploratory factor analysis.

Variable	Item	1	2	3	4	5	6	Cronbach α
Intention to consent	INT1	0.96	0.03	-0.01	0.00	0.02	-0.01	0.97
	INT2	0.96	0.04	-0.03	0.01	0.03	-0.02	
	INT3	0.94	-0.04	0.05	-0.01	0.04	0.02	
Social influence	SI1	0.01	0.93	-0.01	0.02	-0.01	0.03	0.93
	SI2	-0.04	0.97	-0.01	-0.03	0.00	-0.04	
	SI3	0.05	0.88	0.03	0.03	0.04	0.01	
Trust in health professionals	THP1	0.02	0.03	0.92	0.03	0.03	0.00	0.92
	THP2	-0.03	-0.02	0.93	-0.02	0.03	0.02	
	THP3	0.03	0.00	0.86	0.01	0.06	-0.03	
Privacy concerns	PC1	0.01	0.01	0.00	0.87	0.01	0.03	0.84
	PC2	0.06	-0.01	0.07	0.85	-0.13	0.05	
	PC3	-0.07	0.01	-0.05	0.87	0.03	-0.06	
Perceived usefulness	PU1	0.04	0.02	0.00	-0.04	0.85	0.05	0.88
	PU2	0.04	0.03	0.12	-0.09	0.75	0.00	
	PU3	0.03	-0.01	0.06	0.03	0.86	-0.04	
Health concerns	HC1	0.00	-0.03	0.06	0.01	-0.02	0.89	0.78
	HC2	0.05	0.06	0.00	-0.11	-0.19	0.88	
	HC3	-0.07	-0.02	-0.09	0.15	0.27	0.72	

Bold numbers indicate high loadings.

(VIF) was used. According to Tabachnick and Fidell [57], a VIF greater than 10 suggests an existence of multicollinearity between factors. Table 4 shows the VIF for all variables; the maximum VIF is 1.90 which is well below the threshold of 10. Therefore, the results show that the model does not suffer from multicollinearity.

4. Results

SAS 9.4 was used to recode the data and AMOS 24 was used to run the analysis. Structural equation modeling (SEM) was used to test the hypothesized model. Estimates derived from the SEM analysis were used to test the research hypotheses. Table 5 shows the results for three models: Model 1 includes all participants, Model 2 includes participants of the Binary Sharing Setting group, and Model 3 includes participants of the Customized Sharing Setting group. The first section of the results reports the overall relationships between each of the independent variables and the intention to consent. It also shows the direct impact of granting greater control to the patient on the intention to consent. The second section of the results shows the relationships for each of the two groups [(A) Binary (B) Customized] and the difference in the relationships between the groups.

4.1. Overall influence

Fig. 3 shows the results for the overall impact of greater patient control in sharing PHI on the intention to consent, as well as the overall influence of the independent variables on intention to consent. The model includes all 388 participants, and overall the values of fit statistics of the structural model indicate a good model fit. For example, the CFI = 0.976, TLI = 0.971, RMSEA = 0.044, and $\chi^2/df = 1.739$ indicate an excellent model fit [53]. The model explains 50.1% of the variation in the intention to the consent variable, which indicates an excellent R² [58].

The path coefficient of the customized sharing setting (CSS) in model 1 is positive and significant ($\beta_{CSS} = 0.283, p < .001$), supporting Hypothesis 1 and indicating a significant increase in the intention to consent through granting patients greater control in sharing their PHI.

Hypothesis 2a proposes a negative relationship between privacy concerns and the intention to consent. The path coefficient was negative and significant ($\beta_{PC} = -0.149, p < .01$), suggesting that in general more extensive privacy concerns yield a lower intention to share,

Table 4
Correlation, validity, and multicollinearity.

	VIF	1	2	3	4	5	6	
Intention to consent	NA	0.909						
Privacy concerns	1.65	-0.315	0.633					
Perceived usefulness	1.90	0.588	-0.360	0.71				
Social Influence	1.25	0.427	-0.142	0.421	0.815			
Health concerns	1.15	0.001	0.262	-0.062	0.056	0.561		
Trust in HP	1.78	0.485	-0.317	0.637	0.358	-0.083	0.796	
Male	1.05	-0.024	-0.013	0.006	0.005	0.097	0.013	NA
# of Chronic diseases	1.06	0.057	-0.005	0.047	0.011	0.198	0.045	0.130

Bold numbers in diagonal represent the AVE for each variable.

Table 5
SEM results for all models dependent variable: intention to consent.

Variable	Model		
	1-All	2-Binary	3-Customized
	Standardized estimate		
Privacy concerns	-0.149**	-0.179***	-0.124*
Social influence	0.208***	0.189*	0.27***
Trust in healthcare Professionals	0.106*	0.085	0.183**
Health concerns	0.079*	0.12*	0.033
Perceived usefulness	0.375***	0.369***	0.409***
Customized sharing setting	0.283***	NA	NA
Male	0.029	0.05	-0.002
# of Chronic diseases	0.034	0.049	0.036
N	388	195	193
<i>SEM model fit indices</i>			
CFI	0.976	0.976	0.967
TLI	0.971	0.97	0.96
RMSEA	0.044	0.048	0.053
X ² /DF	1.739	1.453	1.531

*** $P < 0.001$.
** $P < 0.01$.
* $P < 0.1$.

thus supporting **Hypothesis 2a**. These results suggest that privacy concerns are a barrier to the sustainability of HIEs.

Hypothesis 3a posits the existence of a positive association between social influence and the intention to consent. The results supported this hypothesis: $\beta_{SI} = 0.208, p < .001$. Indeed, the path coefficients for trust in HIEs were positive and significant.

Hypothesis 4a suggests the existence of a positive association between trust in healthcare professionals and the intention to consent. The results provided support for this hypothesis: $\beta_{THP} = 0.106, p < .1$. The path coefficient for trust in healthcare professionals was positive and significant.

Hypothesis 5a states that health concerns positively influences the intention to consent. The path coefficient for health concerns was positive and significant: $\beta_{HC} = 0.079, p < .1$. Higher health concerns appears to yield higher intention to consent. Thus, **Hypothesis 5a** is supported.

Finally, **Hypothesis 6a** proposed a positive relationship between perceived usefulness and the intention to consent. The path coefficient of perceived usefulness in this model was positive and significant: $\beta_{PU} = 0.375, p < .001$. These results supported **Hypothesis 6a** and suggest that perceived usefulness motivates higher consent rate.

4.2. Sharing setting differences

Table 5 shows the impact of the predictor variables on the outcome variable for each of the sharing settings (Binary and Customized), as

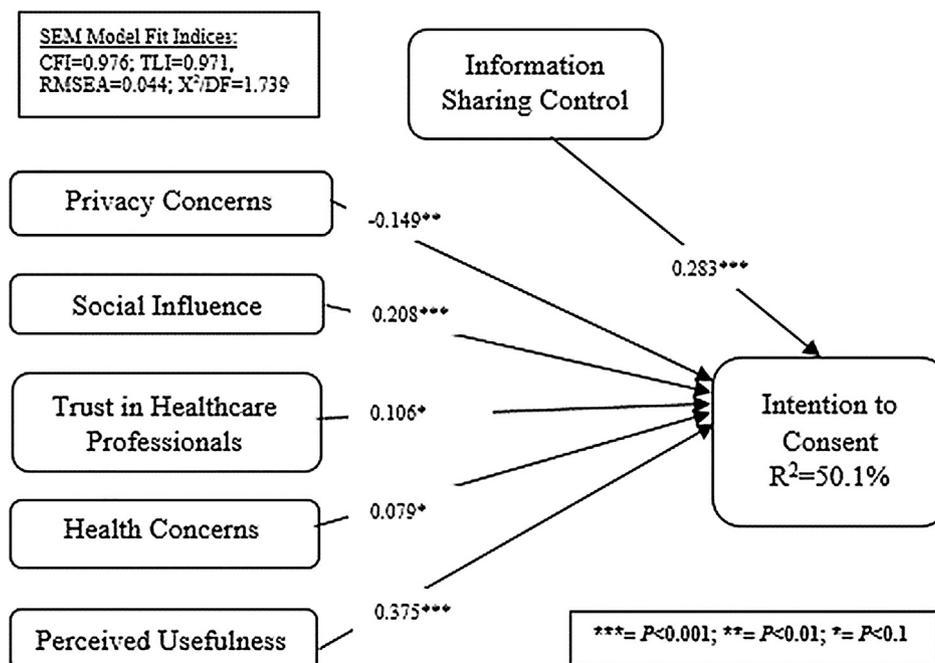


Fig. 3. SEM results for the overall model.

well as the overall influence of the predictor variables on the intention to consent. The fit statistics indicated a strong model for each of the three models: the RMSEA ranged from 0.044 to 0.053, CFI ranged from 0.967 to 0.976, and TLI ranged from 0.96 to 0.971. The model was assessed using the χ^2/df ratio, which ranged from 1.453 to 1.739, indicating a good fit for all models [59].

The results show that several differences occur in the effects of the determinants on intention to consent between the two groups. **Hypothesis 2b** proposes a difference in the influence between privacy concerns and the intention to consent between the two groups. The results (Table 5) support this hypothesis. Although privacy concern is negative and significant in both groups, results indicate a higher influence of privacy concerns on the intention to consent for the Binary group compared to the Customized group. The negative impact privacy concerns on intention to consent is about 44% higher when patients are exposed to a binary sharing setting. Thus, privacy is a bigger barrier when the sharing mechanism is not flexible.

Hypothesis 3b suggests a change in the relationship between social influence and the intention to consent between the two groups. Social influence remains a significant and positive under both sharing settings; however, social influence has a higher impact under the Customized sharing setting. The magnitude of the social influence variable increases by almost 50% under the Customized setting compared to Binary setting. This finding supports **Hypothesis 3b** and suggests that offering flexible sharing settings empowers the role of social influence.

Hypothesis 4b states that the association between trust in healthcare professionals and the intention to consent is different in the two sharing settings. The results show that trust in healthcare professionals is not significantly associated with intention to consent for the Binary setting group, but positive and significant for the Customized setting group, thus providing support for **Hypothesis 4b**. This result suggests that establishing higher trust between patients and healthcare professionals will not increase consent rate when the sharing setting is very rigid. Offering flexible sharing settings will empower the role of trust in increasing consent rate.

Hypothesis 5b proposes a difference between the two sharing settings in the impact of health concerns on the intention to consent. The results (Table 5) show that health concerns have no significant influence on the outcome variable under the customized sharing setting, while the relationship is positive and significant under the customized sharing setting. This suggests that consent rate is not dependent on patients' level of health concerns when offered a customized sharing setting. Higher health concern is needed to engage patients in HIEs when the sharing mechanism is not flexible.

Finally, **Hypothesis 6b** posits that perceived usefulness will have a different effect on the intention to consent under the two sharing settings. The findings provide support for this hypothesis. The path coefficient is positive and significant under both sharing settings. However, customized sharing settings empower the role of perceived usefulness in engaging more patients in the system through higher intention to consent. The customized sharing setting increases the importance of the usefulness of the system by about 10%. Thus, flexible sharing mechanism improves the role of perceived usefulness in generating higher consent rates.

5. Discussion

The findings suggest that offering more flexible sharing settings will help in increasing consent rate and thus engage patients in HIEs, despite the existing concerns (i.e. privacy concerns). The current case of the sharing mechanism in HIEs offers no choice for patients to choose what information to share or with whom. This finding provides insight to policy makers by proposing a sharing mechanism that will improve the sustainability of HIEs.

The findings also suggest that a customized sharing setting helps mitigate the negative influence of privacy concern on the intention to

consent by about 40%. In general, privacy concerns are a barrier to patients' consent. Privacy concerns remain a barrier under both sharing settings; however, greater flexibility reduces the negative impact of privacy concerns on sharing PHI.

Of all the factors associated with the intention to consent, perceived usefulness of the systems has the highest impact on driving higher consent rate. More importantly, offering a customized sharing setting to the patient empowers the role of the perceived usefulness and thus results in yet higher consent rate. Similarly, customized sharing settings empower the role of trust in healthcare professionals and social influence in increasing patients' intention to consent. Thus, customized sharing settings improve the role of motivators and reduce the role of barriers to consent in HIEs. These results suggest that flexible sharing settings have both a direct and an indirect role in improving patients' engagement in the system.

6. Conclusion

The motivation for this research comes from the desire to sustain HIEs by engaging more patients with greater power, without sacrificing their privacy. Currently, patients are passive consumers of HIEs services, and their role is restricted to signing a consent form. This research proposes a way to improve the consent rate in HIEs. The findings show that granting patients greater control in sharing their PHI increases consent rate significantly and thus results in sustaining HIEs and engaging patients in their health. These findings are significant from a practical perspective, as they make patients more vested in HIEs. This allows for revenue generating opportunities to help the sustainability of HIEs. This research also makes several contributions to research. It extends the UTAUT model by using it in a healthcare IT context. Another theoretical contribution is 'health concerns' as a driver for patient consent. This has not been studied as part of prior literature and is another contribution to the existing body of literature on HIEs and the UTAUT model.

This study also investigates the change in the UTAUT model under different sharing settings. The results indicate that greater control to patients changes the relationship between each of the predictor variables and the outcome variable. Thus, the patients' acceptance and use of the technology changes because of a change in the flexibility of sharing. These results provide theoretical implication on how the UTAUT model is different based on the level of control provided to the patients. This study also provides practical implication for healthcare providers to sustain HIEs by incorporating a more flexible sharing mechanism that adds value to patients and encourages them to consent to HIEs. This study contributes to practice by proposing a sharing mechanism that will improve the sustainability of HIEs by engaging more patients.

7. Limitation and future work

This research investigates the factors associated with intention to consent and the influence of sharing settings on intention and on the relationship between each of the predictor variables and the intention to consent. The study measures the intention to consent, but it does not provide evidence for actual use behavior. However, intention is a very strong prediction of actual behavior. In addition, perceived ease of use, which is typically a key factor influencing intention to use, was excluded in this study. That is because while the patients consent to HIE by signing a piece of paper, the patients never interact with the system. The healthcare providers use the system to upload information or to retrieve patients' information. Since this study focuses on the patient's side of the equation and the patient does not directly interact with the system, therefore ease of use is not appropriate for the context.

This study utilizes two types of sharing settings; future research might include several levels of sharing settings, such as only controlling what information to share or only controlling with whom to share the

information. Further, the difference in the relationships between each of the predictor variables and the intention to consent are worth investigating. In addition, it will be stimulating to investigate the providers' side of the equation, for example providers' trust the information within HIE and their perception of the usefulness of HIEs."

Conflict of interest

I declare that I have no significant competing financial, professional or personal interests that might have influenced the performance or presentation of the work described in this manuscript.

References

- [1] G.J. Kuperman, Health-information exchange: why are we doing it, and what are we doing? *J. Am. Med. Inform. Assoc.* 18 (5) (2011) 678–682.
- [2] M. Tripathi, et al., Engaging patients for health information exchange, *Health Aff.* 28 (2) (2009) 435–443.
- [3] M.F. Furukawa, et al., Despite substantial progress in EHR adoption, health information exchange and patient engagement remain low in office settings, *Health Affairs* (2014), <http://dx.doi.org/10.1377/hlthaff.2014.0445>.
- [4] H. Li, et al., Examining the decision to use standalone personal health record systems as a trust-enabled fair social contract, *Decis. Support Syst.* 57 (2014) 376–386.
- [5] M. Abdekhoda, et al., The effects of organizational contextual factors on physicians' attitude toward adoption of Electronic Medical Records, *J. Biomed. Inform.* 53 (2015) 174–179.
- [6] N. Yaraghi, et al., Drivers of information disclosure on health information exchange platforms: insights from an exploratory empirical study, *J. Am. Med. Inform. Assoc.* (2015) ocv086.
- [7] K. Caine, R. Hanania, Patients want granular privacy control over health information in electronic medical records, *J. Am. Med. Inform. Assoc.* (2012) amiajnl-2012-001023.
- [8] T. Adams, et al., Lessons from the central Hampshire electronic health record pilot project: issues of data protection and consent, *BMJ* 328 (7444) (2004) 871–874.
- [9] A. Hassol, et al., Patient experiences and attitudes about access to a patient electronic health care record and linked web messaging, *J. Am. Med. Inform. Assoc.* 11 (6) (2004) 505–513.
- [10] J.S. Ancker, et al., Consumer perceptions of electronic health information exchange, *Am. J. Prev. Med.* 43 (1) (2012) 76–80.
- [11] S.R. Simon, et al., Patients' attitudes toward electronic health information exchange: qualitative study, *J. Med. Internet Res.* 11 (3) (2009).
- [12] D. Grande, et al., Public preferences about secondary uses of electronic health information, *JAMA Intern. Med.* 173 (19) (2013) 1798–1806.
- [13] C.M. Angst, R. Agarwal, Adoption of electronic health records in the presence of privacy concerns: the elaboration likelihood model and individual persuasion, *MIS Quart.* 33 (2) (2009) 339–370.
- [14] R.V. Dhopeswarkar, et al., Health care consumers' preferences around health information exchange, *Ann. Family Med.* 10 (5) (2012) 428–434.
- [15] J. Platt, S. Kardia, Public trust in health information sharing: implications for bio-banking and electronic health record systems, *J. Personal. Med.* 5 (1) (2015) 3–21.
- [16] L. Dimitropoulos, et al., Public attitudes toward health information exchange: perceived benefits and concerns, *Am. J. Manage. Care* 17 (2011) 12.
- [17] E.R. Weitzman, et al., Willingness to share personal health record data for care improvement and public health: a survey of experienced personal health record users, *BMC Med. Inform. Decision Making* 12 (1) (2012) 39.
- [18] W.A. Yasnoff, L. Sweeney, E.H. Shortliffe, Putting health IT on the path to success, *JAMA* 309 (10) (2013) 989–990.
- [19] E.M. Demirezen, S. Kumar, A. Sen, Sustainability of healthcare information exchanges: a game-theoretic approach, *Inf. Syst. Res.* (2016).
- [20] N. Yaraghi, et al., Health information exchange as a multisided platform: adoption, usage, and practice involvement in service co-production, *Inf. Syst. Res.* 26 (1) (2014) 1–18.
- [21] V. Venkatesh, et al., User acceptance of information technology: toward a unified view, *MIS Quart.* (2003) 425–478.
- [22] J.L. Fernández-Alemán, et al., Security and privacy in electronic health records: a systematic literature review, *J. Biomed. Inform.* 46 (3) (2013) 541–562.
- [23] D. Gefen, E. Karahanna, D.W. Straub, Trust and TAM in online shopping: an integrated model, *MIS Quart.* 27 (1) (2003) 51–90.
- [24] H. Cavusoglu, et al., Assessing the impact of granular privacy controls on content sharing and disclosure on Facebook, *Inf. Syst. Res.* 27 (4) (2016) 848–879.
- [25] P. Slovic, *The Perception of Risk*. Risk, Society, and Policy Series, Earthscan, London, 2000.
- [26] L. Brandimarte, A. Acquisti, G. Loewenstein, Miscalibrated confidences: privacy and the control paradox, *Soc. Psychol. Personal. Sci.* 4 (3) (2013) 340–347.
- [27] V.N. Patel, et al., Low-income, ethnically diverse consumers' perspective on health information exchange and personal health records, *Inform. Health Soc. Care* 36 (4) (2011) 233–252.
- [28] M. Abdelhamid, R. Sharman, R. Bezawada, Better Patient Privacy Protection with Better Patient Empowerment about Consent in Health Information Exchanges, 2015.
- [29] A.F. Westin, *Privacy and Freedom*, Atheneum. New York, 1967, pp. 7.
- [30] M. Abdelhamid, J. Gaia, G.L. Sanders, Putting the focus back on the patient: how privacy concerns affect personal health information sharing intentions, *J. Med. Internet Res.* 19 (9) (2017).
- [31] R. Cushman, et al., Ethical, legal and social issues for personal health records and applications, *J. Biomed. Inform.* 43 (5) (2010) S51–S55.
- [32] V. Venkatesh, F.D. Davis, A theoretical extension of the technology acceptance model: four longitudinal field studies, *Manage. Sci.* 46 (2) (2000) 186–204.
- [33] J.M. Levine, R.L. Moreland, *Small Groups: Key Readings*, Psychology Press, 2008.
- [34] S.T. Fiske, S.E. Taylor, *Social Cognition: From Brains to Culture*, Sage (2013).
- [35] J. Kim, H.-A. Park, Development of a health information technology acceptance model using consumers' health behavior intention, *J. Med. Internet Res.* 14 (5) (2012) e133.
- [36] S. Venkatesan, et al., Internet as preferred health information source: an information foraging, *Perspective* (2016).
- [37] H. Li, et al., Examining the decision to use standalone personal health record systems as a trust-enabled fair social contract, *Decis. Support Syst.* 57 (2012) 376–386.
- [38] P.A. Teixeira, et al., HIV patients' willingness to share personal health information electronically, *Patient Educ. Counsel.* 84 (2) (2011) e9–e12.
- [39] B. Bulgurcu, H. Cavusoglu, I. Benbasat, Information security policy compliance: an empirical study of rationality-based beliefs and information security awareness, *MIS Quart.* 34 (3) (2010) 523–548.
- [40] N. Yaraghi, *The Benefits of Health Information Exchange Platforms Measuring the Returns on a Half a Billion Dollar Investment*, Center for Technology Innovation at Brookings, 2015.
- [41] N. Yaraghi, An empirical analysis of the financial benefits of health information exchange in emergency departments, *J. Am. Med. Inform. Assoc.* (2015) ocv068.
- [42] C.M. Carr, et al., Observational study and estimate of cost savings from use of a health information exchange in an academic emergency department, *J. Emergency Med.* 46 (2) (2014) 250–256.
- [43] C. Williams, et al., From the Office of the National Coordinator: the strategy for advancing the exchange of health information, *Health Affairs* 31 (3) (2012) 527–536.
- [44] P. Fontaine, et al., Health information exchange: participation by Minnesota primary care practices, *Arch. Intern. Med.* 170 (7) (2010) 622–629.
- [45] R. Ayyagari, V. Grover, R. Purvis, Technostress: technological antecedents and implications, *MIS Quart.* 35 (4) (2011) 831–858.
- [46] Z.R. Steelman, B.I. Hammer, M. Limayem, Data collection in the digital age: innovative alternatives to student samples, *MIS Quart.* 38 (2) (2014) 355–378.
- [47] N.K. Malhotra, S.S. Kim, J. Agarwal, Internet users' information privacy concerns (IUIPC): The construct, the scale, and a causal model, *Inf. Syst. Res.* 15 (4) (2004) 336–355.
- [48] F. Wu, *User Acceptance of Community Emergency Alert Technology: Motivations and Barriers*, ProQuest, 2009.
- [49] T. Dinev, P. Hart, An extended privacy calculus model for e-commerce transactions, *Inf. Syst. Res.* 17 (1) (2006) 61–80.
- [50] C.L. Anderson, R. Agarwal, The digitization of healthcare: boundary risks, emotion, and consumer willingness to disclose personal health information, *Inf. Syst. Res.* 22 (3) (2011) 469–490.
- [51] F.D. Davis, Perceived usefulness, perceived ease of use, and user acceptance of information technology, *MIS Quart.* (1989) 319–340.
- [52] R.K. Jayanti, A.C. Burns, The antecedents of preventive health care behavior: An empirical study, *J. Acad. Mark. Sci.* 26 (1) (1998) 6–15.
- [53] L.T. Hu, P.M. Bentler, Cutoff criteria for fit indexes in covariance structure analysis: Conventional criteria versus new alternatives, *Struct. Equat. Model.: Multidiscipl. J.* 6 (1) (1999) 1–55.
- [54] K. Joreskog, D. Sorbom, *LISREL 7: User Reference Guide Scientific Software*, Chicago, 1989.
- [55] J.C. Nunnally, I. Bernstein, The assessment of reliability, *Psychometr. Theory* 3 (1) (1994) 248–292.
- [56] C. Fornell, D.F. Larcker, Structural equation models with unobservable variables and measurement error: Algebra and statistics, *J. Market. Res.* (1981) 382–388.
- [57] B. Tabachnick, L. Fidell, *Using multivariate statistics (6th international edition (cover). ed.)*, Boston [Mass.], 2013.
- [58] J. Cohen, Statistical power analysis, *Curr. Directions Psychol. Sci.* 1 (3) (1992) 98–101.
- [59] J.-B.E. Steenkamp, H. Baumgartner, Assessing measurement invariance in cross-national consumer research, *J. Consum. Res.* 25 (1) (1998) 78–90.