Sharing Personal Health Information: Personalization versus Privacy

Full Paper

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Abstract

Personal health information (PHI) is increasingly becoming a critical component of personalized healthcare. However, investment in PHI capabilities may be severely undermined if consumers are unwilling to share PHI. While consumers are concerned about potential compromise of PHI, they also value the personalization benefits of PHI use. In light of the limited understanding of this tension, this research develops a parsimonious model to predict consumer’s willingness to share PHI as a result of the tradeoff between concern for privacy and value for personalization. Grounded on theoretical positions of Information Boundary Theory, we examine the mechanism through which privacy concern and personalization influence willingness to share PHI. Results of the study suggests that the attitude towards sharing PHI is shaped by two competing forces of privacy concerns and value for personalization. Insights from the study can be used to craft future healthcare implementation policies.

Keywords

Personal health information, personalization-privacy paradox, information sharing behavior

Introduction

Personal health information (PHI) makes it possible for healthcare providers to personalize care through secure use of health information. PHI typically refers to the patient’s information related to medical history, test and laboratory results, medication information and other data collected for the purpose of medical care (IOM 2012). The rapid digitization of healthcare has led to generation of vast amount of sensitive PHI as digitized output. As healthcare organizations continue to generate vast amount of sensitive PHI, safeguarding such information has become the key focus of the stakeholders (Kush et al. 2008; Liedtke 2008; Mandle and Kohane 2008; Tang et al. 2006). While healthcare institutions continue to invest in health IT to improve healthcare outcomes, consumer concern about PHI is becoming a major constrain in the appropriation of benefits from such systems (Agarwal and Angst 2006; Glaser et al. 2008). Consumer concern reflects the tension between the perception of benefits emanating from the use of PHI and the lack of control over such information (Federal Trade Commission 2010; IOM 2012). A recent report on patient privacy and data security suggested that the healthcare industry incurred a loss of USD 5.6 billion due to breach of PHI (Sullivan 2014). The significance of PHI to the healthcare system can be highlighted by the fact that the enforcement of privacy rule is governed by the Office of Civil Rights. The growing discourse on the potential of PHI to increase efficiency and lower healthcare costs is increasingly focusing on the consumer perspective related to access and disclosure of such sensitive personal information (Agrawal et al. 2010; Fichman et al. 2011; Kaelber et al. 2008). The rapid digitization of healthcare implies that increasingly patient health records are being accessed across much wider range of healthcare settings, which subsequently increases the number of potential recipients of the digitized records (Blumenthal and Tavenner 2010). Keeping in context the highly sensitive nature of PHI and the numerous stakeholders with interest to gain access to PHI, the risk of compromise is relatively high (Beckerman 2008; Rohm and Milne 2002; Willison et al. 2007). The high degree of risk coupled with the varying attitude towards digital records forms a major constrain for meaningful use of such technologies (Willison et al. 2007).

For healthcare institutions, privacy and security of PHI is a critical concern that healthcare managers have to deal in their transactions with healthcare consumers. Although consumers value the benefits accruing
from the use of PHI, they are increasingly faced with the tension between growing concerns about the privacy of information and the need for personalization. This tension, also known as the personalization-privacy paradox, is bound to increase as healthcare institutions rapidly digitize the healthcare processes. Knowledge about its implication on consumers’ willingness to share PHI is critical to policy makers as well as healthcare institutions, as attitude towards consent and disclosure can potentially impact meaningful use of healthcare information technology (HIT). However, addressing the paradox is a complicated issue, since personalized care – a capability that user’s value – often requires the utilization of PHI. The usage of PHI is the root of consumer concerns related to privacy. Given the importance of information sharing behavior in the healthcare context, development of theoretical perspective is one of the key objectives of this study. Collectively, extant literature highlights the need for further research on consumer attitude and belief towards sharing of PHI (Angst and Agarwal 2009; Anderson and Agarwal 2011).

In light of the limited knowledge and understanding of this paradox, the focus of the paper is to provide a plausible theoretical rational for the mechanism underlying the willingness to share PHI. Specifically this research examines two research questions: How does individual's value for personalization and health information privacy concern effect willingness to share PHI? How does trust in the digital medium influence the relationship among these three constructs? While literature points to the role of trust in the tension, the mechanism through which trust influences the paradox relationship is not clear. The paper uses the Information Boundary Theory framework to examine the research questions. The main construct of interest in this paper is consumers’ willingness to share PHI with healthcare organizations and other stake holders (e.g., insurance agencies, government). Willingness to share PHI reflects the individual’s willingness to provide access to PHI in the electronic format (Anderson and Agarwal 2011). In the following sections, we discuss the theoretical background, present rationale for our hypotheses, the methodology pursued and the results observed. Finally, we discuss the theoretical and practical implications and offer future research directions.

**Theoretical Background**

This section summarizes prior research in the key areas of focus. This section first introduces the theoretical lens – i.e., Information Boundary Theory. The section subsequently discusses prior literature on healthcare privacy concerns and the role of trust in the context of information sharing behavior in the healthcare context.

*Information Boundary Theory*

We use the Information Boundary Theory (IBT) as the guiding theoretical lens to anchor the proposed relationship. IBT explains the psychological processes individuals use to control the outflow of private information to other parties (e.g., hospitals, government) (Stanton 2003; Stanton and Stam 2003). The IBT theory posits that individuals form informational spaces around themselves with defined boundaries and these boundaries play pivotal roles in their willingness to disclose or hide information (Petronio 1991; Stanton and Stam 2003). Individuals are conscious of the value of personal information and its potential use or misuse. This is reflected in the strategic approach taken while revealing or withholding information. The theory argues that there are two different end states: *promotion focused* and *prevention focused*. Promotion focused end state concentrates on the motivating power of achieving benefits from the disclosure of personal information, whereas prevention focused end state emphasizes the motivating power of avoiding or mitigating losses due to disclosure. Any attempt to cross the personal information boundary will be perceived as an invasive act (Solove 2006). The extent to which an individual perceives such crossing of boundary to be intrusion is contingent on the extent to which the individual perceives the disclosure as beneficial or harmful (Petronio 1991). The type and nature of the information also plays a key role in accessing the tradeoff. For instance, health information has a greater influence compared to any other types of information (e.g., social security, financial). IBT is well suited to examining attitude towards PHI because of the rich theoretical explanatory mechanisms provided by the lens – i.e., mechanism associated with cost benefit trade off analysis. In the present context, the theory can capture the psychological processes that individuals use to control the flow of sensitive health information. Prior research has extensively used the lens to explain privacy mechanisms while dealing with sensitive information. For example, prior research has used IBT to understand the effect of privacy issues on implementation and acceptance of IT in healthcare context (Zakaria et al. 2003), privacy attitude towards...
communication application (Xue et al. 2008), and privacy attitude related to mobile devices (Sutanto et al. 2013). This present research leverages the IBT to investigate the role of the consumer tension-personalization privacy paradox-on willingness to share PHI.

Healthcare Privacy Concerns

Prior research suggests that PHI elicits greater privacy concern compared to other forms of information such as purchase behavior or personal choice (Gostin and Nass 2009; Kam and Chismar 2006) as “there is little else that is as consequential to an individual as his or her health” (Anderson and Agarwal 2011 p. 469). Individuals tend to be more concerned about how PHI is used compared to any other individual information (e.g., social security, financial information). Individuals decision to share this kind of PHI is based on levels of trust, on risk and concern associated with health institution storing and utilizing the information (Global Strategy Group 2007; Rohm and Milne 2002), and also on the purpose for which the information is used by the organization (Willison et al. 2009). Healthcare tasks require frequent exchange of information. Such an exchange raises consumer concern for privacy and security (Anderson and Agarwal 2011; Caine and Hanania 2012; Hammond et al. 2003; Hogan and Wagner 1997). This concern for privacy is also reflected in the attitude towards providing consent for the use of this personal information (Kaelber et al. 2008; Kuperman 2011). Specifically, individuals tend to have a negative attitude towards digitized record compared to paper records (Willison et al. 2007).

The frequent exchange of patient data between multiple stakeholders (e.g., hospitals, insurance companies, testing laboratories) increases the perception of fear of PHI compromise and potential for other negative consequences (Anderson and Agarwal 2011; Caine and Hanania 2012). Although technology makes it possible to have parity in the level of transactional security between traditional paper based records and digitized records, perceptions of risk continues to be high for digitized records compared to paper based records (Tang et al. 2006). There is a strong variation in the perception of riskiness towards sharing of paper records versus sharing of digitized records (Civan 2006; Kaelber et al. 2008). Individuals are more suspicious of digital records compared to paper records, therefore unwilling to share personal information for healthcare use. Simultaneously, individuals tend to be more concerned about how organizations handle digital records compared to paper records. However, individuals do recognize that PHI can be used for personalization of healthcare by providing customized service (Angst and Agarwal 2009; Awad and Krishnan 2006).

Since personalization is valued by consumers, addressing privacy concern in this context is complicated. While evidence strongly suggests that consumers are concerned about privacy of PHI, the impact of such concerns may be assuaged by the value for potential personalization benefits. Thus, individuals are willing to forgo privacy concerns if the advantages of personalization is tangible (Chellappa and Sin 2005). This conflict, also known as the personalization-privacy paradox, has been the highlighted at individual level (e.g., Awad and Krishnan 2006; Norber et al. 2007; Sheng et al. 2008; Sutanto et al. 2013; Xue et al. 2011) and also at organizational level (e.g., Lewis 2000; Smith and Lewis 2011). While some studies suggests that privacy triumphs over personalization (e.g., Awad and Krishnan 2006; Sheng et al. 2008), others suggest that personalization benefits may triumph over privacy concerns (Norber et al. 2007; Xue et al. 2011). These conflicting views of consumer response suggest that there needs to be a more theoretical driven interpretation of the personalization-privacy paradox. Also, we know little about how this paradox influences information sharing behavior in the healthcare context. The present research is an endeavor to provide a theoretically driven explanation of the issues of personalization-privacy paradox in this unique context.

Role of Trust

Prior research suggests that trust plays a key role in information sharing behavior (e.g., Dinev and Hart 2006; Gefen 2000). While existing studies have examined the direct influence of trust in the electronic medium on human behavior, little is known about the role of trust as a contingency factor on influencing information sharing behavior in the healthcare context. Furthermore, we have limited understanding of how trust in electronic medium influences the relationship between personalization-privacy tension and willingness to share PHI. In general, high level of trust is a key antecedent of consumers’ willingness to provide consent for use of personal information (Healthcare Financial Management 2007; Willison et al. 2007). Individuals interacting frequently with the digital medium tend to have a more positive view.
towards use of digital records. The level of trust in the storage of PHI is a reflection of the individual's willingness to assume the risks associated with the environment to achieve the desired outcome (Dinev and Hart 2006). Trust in the electronic medium thus refers to the consumer’s belief that digital storage can potentially provide a safe and reliable environment in which to store digitized information (Angst and Agarwal 2009). Individual with high level of trust in the electronic medium tend to believe that the electronic storage format provides the necessary components to facilitate secure electronic storage of health information.

Hypotheses Development

In this section, we theoretically develop our arguments for the hypothesized relationships related to the effect of personalization privacy paradox on willingness to share PHI. **Willingness to share PHI** is defined as the individual's willingness to share PHI in digitized format (Anderson and Agarwal 2011). **Trust in the electronic medium** reflects “the individual's belief that electronic storage provides a reliable and safe environment in which to store health information” (Anderson and Agarwal 2011). **Electronic health information privacy concern** refers to the “anxious sense of interest that an individual has because of various types of threats to the person's state of being free from intrusion” (Malhotra et al. 2004). **Individual's value for personalization** reflects the individual’s perception that personalization using PHI can be used to tailor healthcare products and services. Leveraging on the foundations describe above, Figure 1 reflects the research model for this study.

Compared to any other type of personal information (e.g., social security, financial), PHI is considered to be the most valued personal information and elicits a high level of privacy concern. According to IBT,
individuals will create an informational space around themselves with defined boundary conditions to regulate the flow of such information. Health related information tends to have a rigid boundary and any intrusion into this informational space elicits visceral reaction (Willison et al. 2007). The digital nature of the PHI makes it highly vulnerable to the likelihood of compromise and potential misuse. The ease of replicability makes it especially vulnerable to mala fide and deceptive intention. Individuals will control the flow of information based on assessment of risk and benefits arising out of the flow of such information. In order to avoid a cognitive state of high uncertainty and anxiety, individuals would be less willing to provide PHI and may even hide or misrepresent PHI (Bishop et al. 2005; Son and Kim 2008). Therefore we propose that, high level of health information privacy concerns will be associated with less willingness to share PHI. Thus, we argue:

**Hypothesis 1 (H1):** Electronic health information privacy concern will negatively influence willingness to share PHI.

According to IBT, willingness to share PHI is a motivational driven process that depends on the context of information exchange. Individuals will regulate the flow of personal information on basis of the potential benefit derived from it. Healthcare consumers recognize that electronic records can potentially lead to more personalized medicine, thereby increasing the scope and scale of the effectiveness of the healthcare process. Customers benefit from increased efficiency and reduced costs due to application of personalized and targeted interventions (Kuperman 2011). For example, physicians can reduce the number of clinical tests by using the granular level personal information (e.g., Caine and Hanania 2012). In circumstances where the benefit is evident, IBT theory suggests that individuals will engage in a psychological process termed as promotion focused end states – the motivating power of achieving benefits from the disclosure of PHI. In such circumstances, disclosure of information is not seen as an invasive act (Solove 2006). Since the disclosure is perceived as beneficial, the boundary conditions of the informational space are less rigid. Therefore if individuals have favorable opinion about potential personalization by using PHI then they are more likely to provide consent towards sharing PHI. Thus, we argue:

**Hypothesis 2 (H2):** Individual’s value for personalization will positively influence willingness to share PHI.

The digital artifacts (e.g., EHR) are structures that safeguard transactional success. Individuals trust on the capability of these artifacts to capture, process, and store PHI is critical to ensuring willingness to share PHI. In circumstances where consumer is willing to share PHI, trust in the electronic medium serves to mitigate consumers’ perception of contextual risks inherent in the healthcare environment. IBT suggests that high level of trust mitigates the perception of risk associated with the behavioral outcome. Thus trust in the electronic medium will mitigate the need to focus on prevention end state since potential risk associated with the transaction is lowered. Typically this trust is associated with past technological experience (Kim and Benbasat 2009), which is used towards evaluation of the risk associated with information sharing behavior. This past experiences form a cognitive structure of stable belief system, which can be used towards assessment of cost benefit trade off. Thus, we argue:

**Hypothesis 3a (H3a):** Trust in the electronic medium will negatively affect the relationship between electronic health information privacy concern and willingness to share PHI.

According to the IBT, individuals may loosen control of the outflow of sensitive information to other parties if benefits of personalization are evident. The trust in the digital medium serves to mitigate the risk associated with using the digital medium to capture, store and process PHI. When the benefit of personalization is evident, individuals are more likely to perceive the digital medium as a tool for effectiveness and efficiency (Agarwal et al. 2010). Individual’s technological frame of reference ranges from negative perception to positive perception. While some individuals may see the electronic medium as a necessary evil, others may see the medium as an efficiency and effectiveness enhancing tool. Individuals with high level of trust in the electronic medium are more likely to perceive the medium as a productivity enhancing system that can impact the clinical and patient related care processes. Thus we can argue that this may potentially influence perception of quality of care. This is also consistent with previous findings that greater personalization is associated with higher level of trust on the quality of service (Lee 2005). It also acts as a cue to the consumer that the organization has the competencies to handle PHI and is more likely to safeguard against any nondiscretionary access. On the other hand,
individuals with low level of trust tend to see the potential for personalization skeptically and will be unwilling to share the PHI. Thus, we argue:

**Hypothesis 3b (H3b): Trust in the electronic medium will positively affect the relationship between individual’s value for personalization and willingness to share.**

**Method**

The present research uses Amazon Mechanical Turk (AMT), a popular online crowdsourcing platform (Steelman et al. 2014), as the sampling frame to test the hypothesized relationships. By collecting data from a crowdsourcing platform, it is possible to obtain response with a more diverse set of assumptions. It is also possible to obtain independent participation and also utilize the law of large numbers. Individuals in the crowd also tend to reflect more diversity of anchors and beliefs (Bonabeau 2009). By using the AMT, we were also able to also get a high response rate (84%) for the administered survey. We collected the data by using the registered users of AMT. This allows us to capture the diversity of anchors, beliefs and assumptions to ensure heterogeneity of the sample (Ross et al. 2010). The sample was limited to mainland U.S. to ensure that it resembles the U.S. census demographics. Data for the study was collected through questionnaires administered in a survey using existing validated scales. Measures were adapted from prior studies and contextualized for the healthcare setting. The measure for willingness to share PHI was adapted from Anderson and Agarwal (2011) and was measured using three items on a seven point Likert scale. The scales for trust in the electronic medium was adapted from existing items (Anderson and Agarwal 2011; Dinev and Hart 2006). Individuals’ value for personalization was adapted from Chellappa and Sin (2005). The survey also captures appropriate demographic variables including age, gender, education level and prior privacy violations. To minimize self-report bias, the survey included assurance of respondent anonymity. The final sample consists of 154 respondents. Detailed descriptive statistics for the research constructs are shown in Table 1.

<table>
<thead>
<tr>
<th></th>
<th>Mean</th>
<th>SD</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
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<td></td>
<td></td>
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<td></td>
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<td>.50</td>
<td>.15</td>
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<td></td>
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<td></td>
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<tr>
<td>3. Education</td>
<td>1.57</td>
<td>.72</td>
<td>.01</td>
<td>-.05</td>
<td>NA</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>4. Prior Privacy Violation</td>
<td>1.66</td>
<td>.47</td>
<td>-.20</td>
<td>.17</td>
<td>-.13</td>
<td>NA</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>5. Privacy Concerns</td>
<td>4.44</td>
<td>1.22</td>
<td>.17</td>
<td>-.06</td>
<td>-.14</td>
<td>-.19</td>
<td>NA</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Value For Personalization</td>
<td>4.96</td>
<td>1.05</td>
<td>.80</td>
<td>.01</td>
<td>-.13</td>
<td>.04</td>
<td>-.08</td>
<td>NA</td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. Trust (Electronic Medium)</td>
<td>5.07</td>
<td>1.17</td>
<td>-.14</td>
<td>.12</td>
<td>-.25</td>
<td>.41</td>
<td>-.27</td>
<td>.52</td>
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<td></td>
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<tr>
<td>8. Willingness to Share PHI</td>
<td>4.27</td>
<td>1.63</td>
<td>-.02</td>
<td>-.21</td>
<td>.11</td>
<td>.05</td>
<td>-.03</td>
<td>.31</td>
<td>.26</td>
<td>NA</td>
</tr>
</tbody>
</table>

Notes: *p < .05; **p < .01; ***p < .001

**Table 1: Descriptive Statistics and Correlations**

**Results**

The hypothesized relationships were tested using OLS regression analysis. Table 2 shows the results of the tested models. In the first hypothesis, we proposed a relationship between individual’s concerns for privacy and willingness to share PHI. The coefficient is negative and is not statistically significant (β=.06) suggesting that concerns for privacy may not influence willingness to share PHI directly. This is counter
intuitive to what we argued. Thus we did not find any support for H1. In the second hypothesis, we argued that individual value for personalization will have a positive influence on willingness to share PHI. Our results support our assertion ($\beta=.21^{**}$), thus supporting H2. In the third hypothesis, we argued that trust in the electronic medium will negatively moderate the relationship between individuals’ concern for privacy and willingness to share PHI. We create the interaction term by multiplying the variables (Kenny 2004) and the resultant standardized coefficient measures how the effect of concern for privacy varies and trust in the electronic medium varies. In the second part of the third hypothesis, we argue that trust in the electronic medium will positively moderate the relationship between individuals’ value for personalization and willingness to share PHI. The interactions between privacy concern and trust is not significant, whereas as the interaction between individuals’ value for personalization and trust in the electronic medium is significant. Thus H3a is not supported ($\beta=-.11$) while H3b is supported ($\beta=-.19^{**}$). Although the interaction between individual’s value for personalization and privacy concerns were not hypothesized, the results suggests that there is a significant interaction ($\beta=-.35^{***}$) between these two constructs. The overall model supports two-way interactions between concern for privacy and trust in the electronic medium and individuals’ value for personalization and trust in the electronic medium.

<table>
<thead>
<tr>
<th>Control Variables</th>
<th>Main Effects</th>
<th>Interaction Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>R²</td>
<td>.09</td>
<td>.22</td>
</tr>
<tr>
<td>ΔR²</td>
<td>.13</td>
<td>.14</td>
</tr>
<tr>
<td>β</td>
<td>β</td>
<td>β</td>
</tr>
<tr>
<td>Age</td>
<td>.03**</td>
<td>.02</td>
</tr>
<tr>
<td>Gender</td>
<td>-.22**</td>
<td>-.23***</td>
</tr>
<tr>
<td>Education</td>
<td>.13</td>
<td>.21***</td>
</tr>
<tr>
<td>Prior Privacy Violation</td>
<td>.10</td>
<td>.02</td>
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<tr>
<td>Privacy Concern</td>
<td>.064</td>
<td>-.07</td>
</tr>
<tr>
<td>Value For Personalization</td>
<td>.21**</td>
<td>.22**</td>
</tr>
<tr>
<td>Trust (Electronic Medium)</td>
<td>.22*</td>
<td>.30***</td>
</tr>
<tr>
<td>Privacy Concern × Trust</td>
<td></td>
<td>-.11</td>
</tr>
<tr>
<td>Value For Personalization × Trust</td>
<td></td>
<td>-.19**</td>
</tr>
<tr>
<td>Privacy Concern × Value For Personalization</td>
<td></td>
<td>-.35***</td>
</tr>
</tbody>
</table>

Notes: *p < .05; **p < .01; ***p < .001; 2-tailed

**Table 2. Predicting Willingness to Share PHI**

**Discussion**

Overall, empirical results collectively suggest that willingness to share PHI may not be purely influenced by privacy concerns but also the perceptions of benefit of personalization. We did not find support for the linkage between electronic health information privacy concerns and willingness to share PHI, which is counter intuitive to what we expected. A possible explanation for the counter intuitive finding may lie in limitations our research design. We did not measure the variations in situations which can potentially influence variation in privacy concerns. For example, one such attribute could be human emotions. The emotions attached to the situation may significantly influence individual decision to part with sensitive PHI. Certain medical information such as severity of conditions may potentially influence the level of concerns and subsequently influence the attitude towards information sharing. Another possible explanation for the counter intuitive finding may be the lack of variation in the information type, intended purposes of the PHI, and requesting stakeholders. For instance, individuals may be willing to share PHI to hospitals but not to insurance agencies (Anderson and Agarwal 2011). Given the knowledge that certain health information is more sensitive than others, individuals may show greater concern depending on the nature of health information involved (e.g., Srinivasan and Davis 2014). We found theoretical support for our argument that perceptions of benefits of personalization can influence individual attitude towards providing consent for disclosure and sharing of PHI. A key limitations of the sample is the assumption of
accessibility to internet and computers. Individuals having access to internet and computers are more likely to have positive opinion about the electronic medium. This may potentially bias our results. Another key limitation of the research is the use of perceptual measure compared to the actual usage measure. Intention has been suggested as one of the key predictors of actual behavior (Webb and Sheeran 2006) but perceptual measures tend to be influenced by cognitive biases that can potentially provide faulty inferences (Goes 2013). Apart from issues of limitations associated with the research design, existing healthcare regulatory structures and healthcare privacy laws (e.g., HIPPA rules) limit the usage of actual data. These regulations ensure confidentiality and thus prohibit usage of actual data for academic or commercial use. Even though the study limited data collection to individuals living in U.S, whether or not these insights can be generalized to other countries remain an empirical question. Given the variations in rules, regulations, policies and legal environment, we may find tremendous variation in the attitude towards willingness to share PHI.

The present research makes some key contributions to literature and practice. This research contributes to theory in two ways. First, we contextualized the model to the healthcare setting by specifically focusing on PHI. By contextualizing the study from individual’s willingness to share information to more specific health information, the study expands the understanding to the context where consent and disclosure of personal information is most salient. This study contributes towards highlighting the need to engage extensively in examining healthcare consumer behavior and attitude towards healthcare digitization. By doing so, we address the call for research on more focused theory driven approach on the healthcare consumer perspective (Fichman et al. 2011). Secondly, we extend the IBT by explicitly incorporating trust as a key driver of the disclosure decision. By contextualizing the theoretical framework to the healthcare setting, the research advances and expands scholars' understanding on the nature of relationship between privacy concerns, personalization and trust in the healthcare context. Finally, we extend the IS healthcare literature by providing a plausible theoretical rationale for the mechanism underlying the willingness to share PHI.

Conclusion

The objective of this research is to shed light on one of the key aspect of digitization of healthcare: consumer willingness to share PHI. Certain key considerations motivates our research on this key phenomenon of interest. First, the existing discourse on healthcare privacy concerns suggests that the negative attitude towards disclosure and consent of PHI will always prevail. Furthermore, the discourse tilts towards the rigidity of attitude, suggesting that any effort to change this negative attitude may not yield any positive result. We argue that this may not be the case. Such attitudes do not exist in isolation but are shaped by competing forces of the value for personalization. If individuals are able to see tangible value in deriving personalized benefits then these negative attitudes are very much malleable. Second, there has been focus on the personalization-privacy paradox in variety of domains other than healthcare. This study is an attempt at investigating how this paradox shapes healthcare transformation by investigating how the competing forces of privacy and personalization have any impact on healthcare outcomes. Third, issues of privacy and security are one of the key constraints that prevent healthcare institutions from realizing the full benefit of digitization of healthcare. There is also recognition that IS scholars need to focus considerable attention and effort with respect to the investigation of the variability of beliefs related to privacy and personalization (Agarwal et al. 2010; Fichman et al. 2011). Guided by these primary objectives, the theoretical model seeks to gain a broad-based understanding of individuals' privacy calculus when faced with the need to provide consent to the use and share PHI. We use the theoretical lens of Information Boundary Theory (IBT) to examine the mechanism by which the two competing forces of personalization and privacy influence individual’s willingness to share PHI. Drawing from a nationally representative sample of 154 adults, the study partially supports the core assertion that privacy concerns effect on willingness to share PHI cannot be seen in isolation. Individual’s value for personalization will have a strong influence in shaping individual attitude towards sharing of PHI. Furthermore, individual’s trust in the digital medium may shape the way individuals decide on willingness to provide access and consent for the use of PHI.
References


