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Personalization-Privacy Paradox: Personal Health Information Context

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ABSTRACT

While healthcare institutions continue to invest in personal health information (PHI) capabilities, consumers are increasingly becoming concerned about the use and storage of PHI. At the same time, consumers are increasingly becoming aware of the benefits that accrue from the use of PHI –i.e., the benefits of getting personalized healthcare. We use the Information Boundary Theory (IBT) to examine the effect of this tension–personalization-privacy paradox–on consumers’ willingness to share PHI. We contextualize the theoretical model by integrating the role of discrete contextual factors at play – *trust in the electronic medium*, *information type*, *requesting stakeholder*, and *health status*. In doing so, our research contributes to theory as well as practice. We expand and enrich the IBT by contextualizing it to the healthcare domain. The research contributes to practice by providing insights that can be used as a guide to craft healthcare IT implementation policy. Our/my research also addresses IS communities’ call for more research on consumer perspective.

Keywords

Personal health information, privacy concern, personalization, personalization-privacy paradox, health IT

INTRODUCTION

Personal health information (PHI) is a key component that goes towards ensuring personalized care for healthcare consumers. It broadly refers to the granular level personal information (e.g., patient’s history, test results, laboratory results, medication history, etc.) collected for the purpose of clinical and diagnostic care (IOM 2012). While vast amount of PHI is being consumed and generated due to extensive digitization, privacy and security of such information is a major concern for consumers (Beckerman 2008; Blumenthal and Tavenner 2010; Caine and Hanania 2012; Kush et al. 2008; Tang et al. 2006). The present research is situated in the context of consumer concern related to the access and disclosure of PHI. This concern is increasingly being reflected in the ongoing 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). While consumers value the personalized benefits accruing from the use of PHI, they are also increasingly getting concerned about the compromise of PHI (Kaelber et al. 2008; Karsh et al. 2010). This tension, also known as the personalization-privacy paradox, is increasingly seen in situations where personal information is used towards personalizing products and services (e.g., Awad and Krishnan 2006; Chellappa and Sin 2005; Sutanto et al. 2013). With rapid increase in the level of healthcare automation, it becomes critically important to gain knowledge and insights about its implication on consumers’ willingness to share PHI as appropriation of benefits accruing from healthcare information technology (HIT) is increasingly dependent on the consumer perspective (Agarwal et al. 2010; Fichman et al. 2011). However, addressing the personalization-privacy paradox is a complicated issue because personalization of health care – a capability that user’s value – often requires the extensive utilization of PHI. Motivated by the importance of PHI to healthcare, the objective of the proposed research is to develop a theoretically driven perspective on mechanisms influencing consumer’s willingness to share PHI. Collectively, prior literature in this context highlights the need for more critical examination of the consumer attitude towards sharing of PHI (Agarwal et al. 2010; Angst and Agarwal 2009; Anderson and Agarwal 2011; Civian et al. 2006).

In light of the limited knowledge and understanding of this paradox, the focus of the present research is to provide a plausible theoretical rational for the mechanism underlying consumers’ willingness to share PHI. Specifically this research examines two research questions: *How does personalization-privacy paradox impact willingness to share PHI? How do contingency factors such as trust in the electronic medium, type of information, requesting stakeholder, and health status influence the relationship between the paradox and the willingness to share PHI?* The paper uses the *Information Boundary Theory* framework as the lens to develop some key hypotheses. The key

construct of interest is consumers' willingness to share PHI. Willingness to share PHI refers to the individual's willingness to provide access and disclosure to PHI (Anderson and Agarwal 2011).

THEORETICAL BACKGROUND AND PRIOR RESEARCH

The present research uses the Information Boundary Theory (IBT) as the guiding theoretical perspective to anchor the proposed relationship. IBT provides a theoretical mechanism to explain the psychological processes individual use to control and regulate the outflow of private information to other parties (e.g., hospitals, government) (Stanton 2003; Stanton and Stam 2003). The theory posits that individuals create an informational boundary around themselves to regulate such flow. Any attempt to cross this informational boundary is seen as an invasive act (Solove 2006). However, individuals are likely to allow crossing of this boundary in situation where disclosure of information has tangible benefits (Petronio 1991).

The present research leverages the IBT to examine the personalization-privacy paradox in the context of healthcare information share behavior. Prior literature suggests that individuals are more concerned about PHI compared to any other types of personal information (e.g., social security, financial) (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). Same time, literature also suggests that individuals are willing to forgo privacy concerns if the benefits gained from the use of such information is tangible (Chellappa and Sin 2005; Dhar and Varshney 2011). While this paradox is well documented in many context (e.g., Awad and Krishnan 2006; Norber et al. 2007; Sutanto et al. 2013; Xue et al. 2011), we have limited understanding of how this paradox influences information sharing behavior in the healthcare context. Motivated by limited understanding and the contemporariness of the issues, the present research develops a theoretical model (Figure 1) to explain the paradox in the healthcare domain. Another key objective of the research is to examine the influence of discrete contingency factors in unraveling the personalization-privacy paradox in the context of health information sharing behavior.

RESEARCH MODEL

Leveraging on the foundations mentioned above, Figure 1 reflects the theoretical model.

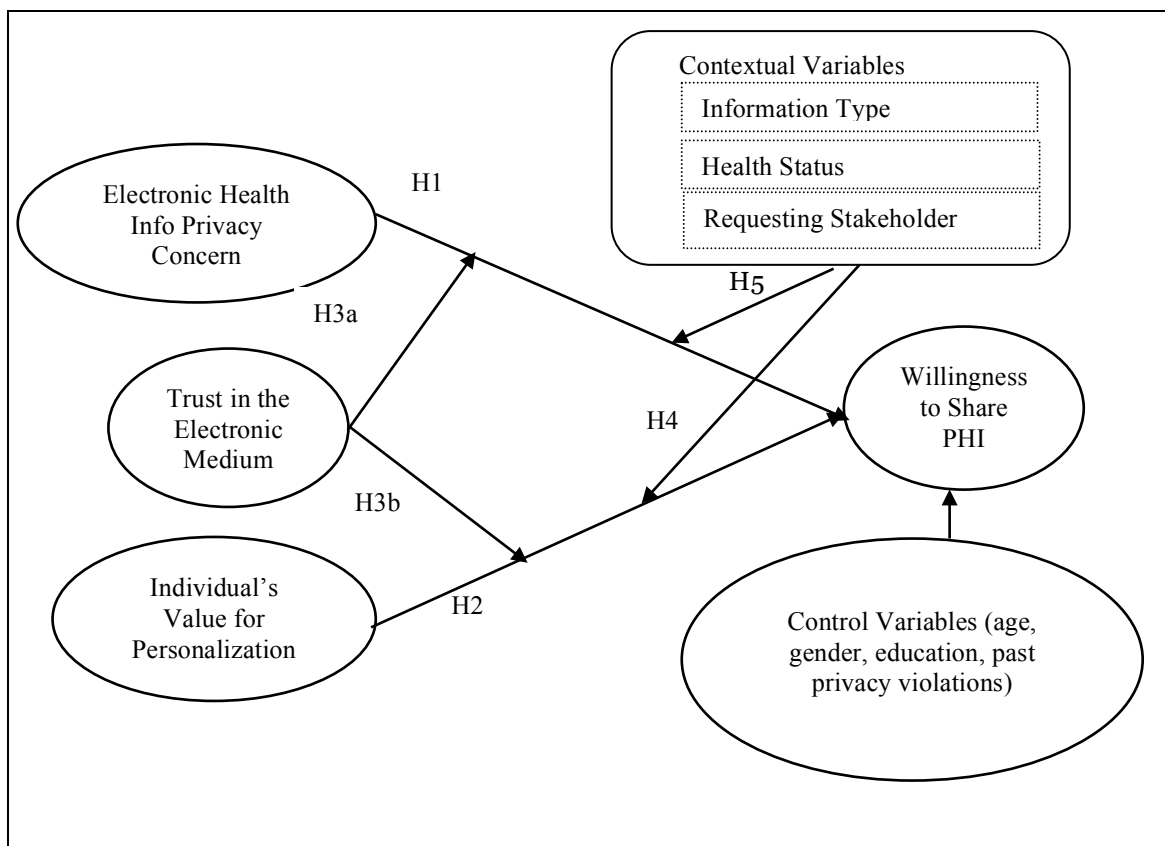


Figure 1. Research Model

According to IBT, individuals will create an informational space around themselves with defined boundary conditions to regulate the flow of sensitive personal 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). However, IBT also suggests that individuals will disclose this sensitive information when tangible benefits are perceived. The digital artifacts (e.g., EHR) also play a key role in influencing the mechanism through which the paradox influences willingness to share PHI. Trust in these digital medium serves to mitigate consumers' perception of risk associated with sharing of PHI. Other aspects that needs to been taken into account are the type of information, individual's health status, and the requesting stakeholder. Some type of health information may be more sensitive than others, thus are less likely to be shared (Rohm and Milne 2004). Same time, individuals are more likely to provide the sensitive information to the physician compared to other requesting stakeholders (e.g., government). Based on these theoretical arguments, we propose these set of relationships:

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

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

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

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

Hypothesis 4 (H4): *The effect of electronic health information privacy concern on willingness to share PHI is contingent on information type, health status, and requesting stakeholder.*

Hypothesis 5 (H5): *The effect of individual's value for personalization on willingness to share PHI is contingent on information type, health status, and requesting stakeholder.*

CONCLUSION

The objective of this research is to shed light on one of the major aspect of healthcare digitization: consumer willingness to share PHI. While extant discourse tend to suggest that the negative attitude towards willingness to share PHI will always prevail, we argue that such conditions are indeed malleable and are shaped by other competing forces - attitude towards personalization. We also bring to focus the contingency factors that influence the impact of the competing attitudes on information sharing behavior in the healthcare context. The present research contributes to theory in two ways. First, the study highlights the need to focus on consumer behavior and attitude towards healthcare digitization. By doing so, we address the call for more focused theory driven approach on the consumer perspective. Secondly, we extend the IBT by explicitly incorporating trust as a key driver of the behavioral outcome. We also extend the IS healthcare literature by providing a plausible theoretical rationale for the mechanism underlying the information sharing behavior in the healthcare context.

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