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The Digitization of Healthcare: Boundary Risks, Emotion, and Consumer Willingness to Disclose Personal Health Information

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As healthcare becomes increasingly digitized, the promise of improved care enabled by technological advances inevitably must be traded off against any unintended negative consequences. There is little else that is as consequential to an individual as his or her health. In this context, the privacy of one's personal health information has escalated as a matter of significant concern for the public. We pose the question: under what circumstances will individuals be willing to disclose identified personal health information and permit it to be digitized? Using privacy boundary theory and recent developments in the literature related to *risk-as-feelings* as the core conceptual foundation, we propose and test a model explicating the role played by type of information requested (general health, mental health, genetic), the purpose for which it is to be used (patient care, research, marketing), and the requesting stakeholder (doctors/hospitals, the government, pharmaceutical companies) in an individual's willingness to disclose personal health information. Furthermore, we explore the impact of emotion linked to one's health condition on willingness to disclose. Results from a nationally representative sample of over 1,000 adults underscore the complexity of the health information disclosure decision and show that emotion plays a significant role, highlighting the need for re-examining the timing of consent. Theoretically, the study extends the dominant cognitive-consequentialist approach to privacy by incorporating the role of emotion. It further refines the privacy calculus to incorporate the moderating influence of contextual factors salient in the healthcare setting. The practical implications of this study include an improved understanding of consumer concerns and potential impacts regarding the electronic storage of health information that can be used to craft policy.

Key words: privacy calculus; healthcare; empathy gap; emotion; communication privacy management
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1. Introduction

> *Privacy Issue Complicates Push to Link Medical Data*: "... Barack Obama's plan to link up doctors and hospitals with new information technology ... is imperiled by a bitter, seemingly intractable dispute over how to protect the privacy of electronic medical records."
>
> Pear 2009. *New York Times*

Today's discourse on the digitization of healthcare has moved beyond the potential transformational effects of artifacts such as electronic health records to a vision of the future in which IT enables the practice and delivery of medicine to be increasingly personalized (Glaser et al. 2008), in much the same way as products and services are customized to the needs and preferences of consumers in commercial domains (Awad and Krishnan 2006). Simultaneously, it has ignited unprecedented concerns regarding the protection of large quantities of personal information that must be captured in electronic health records and other digital databanks. Indeed, the volume and scope of personal health information (PHI) being captured and stored in digital form by both healthcare institutions such as hospitals (Kush et al. 2008) and nonhealth entities such as Google and Microsoft (Liedtke 2008, Mandle and Kohane 2008) is increasing every day, underscoring the urgency of finding appropriate policies to protect consumer privacy while reaping the benefits of digitization.

The specter of PHI being compromised is alarming: a nationwide Harris poll conducted in 2006 confirms that approximately one quarter of U.S. adults have significant concerns about the use of their health information and 50% believe they have lost control of how their medical records are used by insurance companies, employers, and governmental agencies (Harris 2007). Because digitally stored health information represents a considerably faster, cheaper method of access than traditional paper records do (Nakashima 2008), these risks are compounded. Yet, the benefits to be realized by the digitization of health information are compelling: they include reduced medical errors and healthcare costs, improved patient safety, clinical research, improvements in public health monitoring, and increased consumer control over healthcare (Glaser et al. 2008, U.S. Department of Health and Human Services (HHS) 2007, Mowry and Constantinou 2007). Arguably, the social and individual benefits of collecting granular medical data are so considerable that it is important to more fully understand consumer concerns related to health information privacy.

The current environment surrounding digital capture and storage is in a state of heated debate as policy makers, healthcare organizations, and the legal system attempt to evolve appropriate structures and safeguards for the protection of patient privacy. To a large extent, technology, public awareness and concern, and policy are co-evolving; as Lunshof et al. (2008, p. 406) influential work notes, "... new models are needed to offer robust guidance while keeping the reality of a dynamic science in mind." One core guiding principle underlying the debate is that the patient should maintain control over the use of his/her personal information (Mosquera 2009). Thus, to the degree that privacy laws evolve in response to technological changes and consumer demands (Bonner and Chiasson 2005; Solove 2008), it is important to look toward a future in which the consumer is more empowered, a direction in which current policy is evolving (Mosquera 2009). Our research examines consumer willingness to provide access to PHI, irrespective of the specific technologies which might help enforce privacy and/or alter perceptions of privacy. In this manner, we hope to inform changes to policy and related safeguards based on rigorous research.

On the surface, it might appear that the healthcare context is similar to other privacy dilemmas in which individuals engage in a privacy calculus to evaluate the costs and benefits of disclosing personal information (e.g., Dinev and Hart 2006). Yet, arguably, the healthcare context is unique in at least two respects: (1) the nature and variety of risks inherent in the compromise of sensitive health information (Beckerman et al. 2008); and (2) the emotion linked to one's medical state (Trumbo et al. 2007). Prior research suggests that people tend to be more emotional and exhibit greater risk-seeking behavior when faced with a life–death choice than with problems in other life domains such as personal finances or public property (Druckman and McDermott 2008).

Given the rapid pace of transformation in healthcare, it is not surprising that theory development in privacy related to PHI has lagged behind. A dominant theoretical stance in prior research on individual choice under risk or uncertainty, including that underlying extant privacy research (embodied in the privacy calculus), is cognitive and consequentialist (Tversky and Kahnemann 1984, Dinev and Hart 2006). Privacy theories have yet to incorporate emotion as a key construct, despite empirical evidence indicating that emotions have a profound influence on decisions (e.g., Ariely and Loewenstein 2006). In regard to health status, medical condition (e.g., pain, addiction, fear) has been shown to alter preferences and behavior (Loewenstein 2005). Previous studies have also suggested that individuals mis-predict their response in situations where emotions play a significant role (Ariely and Loewenstein 2006). While other types of personal information might evoke an emotional reaction, PHI represents an extreme case because of its highly sensitive nature that elicits a visceral reaction (Druckman and McDermott 2008).

The decision to allow PHI to be digitized is further complicated by the likelihood that individuals differ in their perceptions of the privacy risks and benefits related to sharing their electronic health information, depending on the specific *context* in which they are asked to disclose the information. Three aspects of the context are salient:

(1) The healthcare setting is characterized by multiple types of health information (e.g., mental health, HIV/AIDS status), which are afforded different levels of protection (Beckerman et al. 2008). Prior research has noted that privacy concerns differ across types of information; for example, concerns regarding financial information are deeper as compared with demographic profiles or lifestyle interests (Phelps et al. 2000, Culnan 1993) because the loss associated with a compromise of the former is more consequential than the latter.

(2) The healthcare value chain has multiple players with a need to access and use PHI, and the individual has varied levels and modes of interaction with these organizations (Rohm and Milne 2002, Willison et al. 2007).

(3) A key contextual consideration is the purpose for which information will be used.

How do individuals make PHI disclosure choices in such a complex contextual milieu? To answer this question, we augment the privacy calculus by including the contingency effects of moderating risk scenario variables suggested both in communication privacy management (CPM) theory (Petronio 2002, Stanton 2003) and by health informatics literature (e.g., Beckerman et al. 2008, Jha et al. 2009, Kim et al. 2008, Kohlmeier 2007). Using the privacy calculus, CPM and recent developments in the literature related to *risk-as-feelings* as the core conceptual foundations, in this paper we theorize what type of personal health information an individual is willing to disclose about herself for the purpose of electronic storage, to whom, and for what purposes. We further examine the role of emotion in health information disclosure decisions and the extent to which individuals are able to accurately predict the effect of emotion on their response.

We contribute to theory in three ways. First, we introduce the moderating influence of situational risk factors on the core relationships of the privacy calculus. Second, we extend the privacy calculus to explicitly incorporate emotion as a key driver of the disclosure decision. Third, we contextualize the model to the healthcare setting with the selection of situational risk factors, based on healthcare literature (Beckerman et al. 2008, Dimitropoulos 2007, Willison et al. 2007) and the incorporation of health status emotion (Bowman et al. 2006). We test our theory with data from 1,089 respondents from a nationally representative sample using a quasi-experimental survey methodology.

The rest of this paper is organized as follows. We begin with the theoretical foundations, reviewing prior work on the privacy calculus, the notion of boundaries, and the importance of emotion. This is followed by a discussion of the research model and eight research hypotheses. We next present the results of empirical tests of the model. The paper concludes with a discussion of the theoretical and practical implications of our findings.

2. Theoretical Background and Prior Research

As argued, an understanding of privacy concerns in the digital healthcare context must acknowledge the significance of emotion and involve a consideration of risk that is substantially more granular than has been explored in past privacy studies. The literature on privacy crosses disciplinary boundaries and is extensive. We provide an overview of the major streams of research that our work builds on. We begin by describing key findings and gaps from relevant privacy research,[1] including communication privacy management theory and privacy studies focused specifically on health information. This is followed by a summary of recent literature on the role of emotion in decision making and associated implications for theorizing about privacy concerns.

2.1. Privacy Research

2.1.1. Privacy Research in Information Systems. As argued in expectancy theory, individuals trade-off costs and benefits when deciding whether or not to disclose private information (Culnan and Armstrong 1999), i.e., they engage in a privacy calculus. Expectancy theory broadly supports the notion that a person considers the sum of the valences of all possible outcomes and seeks to maximize positive outcomes and minimize negative outcomes in her motivation to act or not act (Vroom 1964). In information privacy contexts, risks often comprise the cost side of the equation while trust, which reflects a willingness to assume the risks associated with disclosure to achieve some outcome, captures the benefit side (Culnan and Bies 2003, Mayer et al. 1995). Dinev and Hart (2006) found personal Internet privacy concerns, Internet trust, and personal Internet interest to be strongly related to willingness to provide personal information. They also found that a higher level of general perceived Internet risk was related to higher levels of personal Internet privacy concerns and lower levels of willingness to provide personal information. While their study provides useful insight into how Internet users' perceptions of the artifact (i.e., the Internet) influence their behavior, it sheds limited light on the determinants of information disclosure to particular vendors (recipients), or of particular types of information.

Trust is especially crucial in mitigating risk perceptions under conditions of information asymmetry, such as when consumers are unable to accurately determine if a service has been provided correctly because of lack of either expertise or knowledge (Culnan and Armstrong 1999). Research suggests that individuals can be encouraged to disclose to an organization when higher levels of benevolent trust (trustee caring and motivation to act in consumer's best interest) and integrity (trustee honesty) exist (McKnight et al. 2002), as well as when the individual is aware of the organization's use of fair procedures for managing personal information (Culnan and Armstrong 1999). Procedural fairness acts as an intermediary to building trust when relationships are characterized by significant social distance (Culnan and Armstrong 1999).

In an experiment that manipulated the type of information requested (financial and purchase preferences), Malhotra et al. (2004) found that more sensitive information increases risk beliefs and decreases trusting beliefs and intentions to disclose. Phelps et al. (2000) found that consumers were most willing to provide demographic and lifestyle information, less willing to provide purchase-related information, and least willing to provide financial information or personally identifiable information. In the same study,

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[1] A summary of relevant privacy research in health informatics and information systems is available in tabular format in the electronic companion to this paper as part of the online version that can be found at http://isr.journal.informs.org/.

consumers indicated a willingness to provide information in exchange for shopping benefits such as time savings, suggesting that personal interest factors can mitigate privacy concerns (Phelps et al. 2000), consistent with subsequent findings of Dinev and Hart (2006). Culnan (1993) found that although many people hold positive attitudes toward direct marketing in general, they have negative attitudes toward targeted uses of their personal financial information or shopping preferences, which suggests a need to design studies to examine specific characteristics of information practices.

In summary, individuals engage in a decision process to weigh the costs and benefits associated with disclosing information. Although studies have found that trust and concern vary with particular vendors or artifacts or types of information, no single study has combined the potential influence of multiple factors that can influence risk when disclosing personal information. As we argued previously, the complexity of the healthcare context in terms of the plurality of stakeholders, coupled with the highly personal and sensitive nature of the information suggest that investigations of privacy must pay attention to a broad range of risk elements. We next describe literature associated with CPM to help characterize a setting in which multiple contextual factors are likely to play a role, such as is the case in healthcare.

2.1.2. Boundary Management and Contextual Factors. Communication privacy management (CPM) theory presumes people make choices regarding disclosure of personal information based on criteria they perceive as salient at the time the decision must be made (Petronio 2002). CPM uses the metaphor of boundaries to illustrate borders marking the ownership line over which private information flows to aid in understanding control issues (Petronio 2002). When the boundary is open, information flows freely and when it is closed the information flow is restricted. Much of the research on which this theory is based was conducted in interpersonal situations such as marital and parent-child relationships. However, the tradeoff between costs and benefits associated with disclosure in interpersonal situations (Petronio 2002) is similar to the mental calculus performed when determining whether to disclose electronic information to an organization (Dinev and Hart 2006). In both contexts, there are risks associated with disclosure (e.g., loss of friendships or power in interpersonal relationships, or the sale of personal information by organizations to third parties) but also potential benefits (e.g., intimacy in interpersonal relationships, or customized service in relationships between consumers and organizations).

CPM elaborates rules to aid in decisions about how boundaries in dyadic relationships are maintained. Two of these rules shed light on the risk factors that must be considered in the PHI privacy calculus: contextual factors and risk-benefit ratio criteria. First, relevant contextual factors include traumatic events and life circumstances. In the healthcare context, one's medical history might make requests for certain types of information (e.g., mental health or substance abuse) particularly sensitive (Beckerman et al. 2008). Second, the risk-benefit ratio criteria of CPM suggest that an individual accounts for different types and levels of risk when deciding whether or not to disclose information. Types of risk include relational, stigma, face, and security (Petronio 2002). In the healthcare setting, requests for information for different purposes might make different risks salient, thereby influencing the rules applied by the individual when making the disclosure decision.

Stanton (2003) adapted CPM to the workplace setting to understand the conditions under which employees would or would not reveal information to their organizations, incorporating computer-mediated communication with organizational representatives such as managers and supervisors. Using organizational justice concepts, Stanton (2003) found that the opening and closing of boundaries appears to be influenced by the mission-relatedness of the request for information. In other words, the extent to which requests made by employers are perceived as fair and mission-related influences the individual's willingness to disclose. While Stanton's findings shed important light on factors influencing an employee's decision to disclose information in the workplace, additional research is required to improve understanding of how individuals interact with organizations with which they are not employed. Stone et al. (1983) found that information privacy values, beliefs, and attitudes varied with the type of organization involved in the disclosure exchange, with individuals experiencing a greater level of control over information provided to employers and law enforcement agencies than credit granting institutions. In the healthcare context, studies have suggested different levels of trust and concern, depending on the requesting entity (Global Strategy Group 2007, Willison et al. 2007). Acknowledging the degree of variability in stakeholders and their relationships with consumers of healthcare, in 2005 the U.S. Department of Health and Human Services (HHS) created the Health Information Security and Privacy Collaboration (HISPC), a partnership consisting of a multi-disciplinary team of experts in an effort designed to accelerate the secure portability of health information across the United States (HHS 2005). As part of the movement to address privacy and security policy questions, HISPC created scenarios designed to cover a wide range of types of information, as well as the intended use of the information by a wide variety of stakeholders to ensure robust coverage of all procedures/policies because different policies/procedures apply based on these factors (Dimitropoulos 2007). These HISPC scenarios reinforce the importance of numerous contextual factors influencing privacy in the healthcare setting.

In summary, we have argued that the determinants of PHI disclosure decisions are significantly more complex than a simple consideration of concern and trust. As suggested by prior work, to the extent that an individual's perception of risk varies based on situational factors present in the request such as the type of information, the purpose for which that information will be used, and the requesting stakeholder, these three situational factors will alter the salience of the type and level of risk and resulting rules applied to the individual's privacy boundaries. That is, they are likely to interact with concern and trust in the privacy calculus.

2.1.3. Privacy Research in Health Informatics. Although a complete survey of the health informatics literature on privacy of personal health information is beyond the scope of this paper, we summarize a subset here (see tables in the online appendix). Empirical findings in this literature suggest that people are concerned about the privacy of their health information, and that attitudes about sharing information from a paper record versus a digitized version of the record are different (Willison et al. 2007). Consequently, consumers want the ability to provide consent regarding the use of their PHI (Noblin 2007, Simon et al. 2009). The health informatics literature supports the necessity of distinguishing the highly sensitive nature of medical information as opposed to other forms of research-related data, such as purchase behavior and demographics (Kam and Chismar 2006, Rohm and Milne 2002).

Consumers base health information disclosure decisions on their levels of trust, on risk and concern associated with the organization receiving their information (Global Strategy Group 2007, Rohm and Milne 2002), and on the purpose for which their information will be used (Willison et al. 2009). Hospitals are trusted over the government or for-profit organizations (Global Strategy Group 2007), and sharing health information with organizations with lower power, such as grocery and drug stores, is perceived as less threatening than disclosing the same information to insurance companies or employers (Rohm and Milne 2002). In general, consumers want each entity to seek consent (Healthcare Financial Management 2007). In addition, health studies suggest that people desire more control if information is to be used for profit-generating research (Willison et al. 2009) and want to provide consent even if their information is to be used anonymously by third parties (Coy 2001).

Collectively, these studies highlight the need for further research on consumer attitudes and beliefs regarding the privacy of health information. Evidence from this literature suggests that the requesting entity and intended purpose of use influence consumer disclosure decisions, yet the precise nature of this influence is unknown. Prior studies focus solely on main effects and tend not to be grounded in theory. In addition, these studies did not examine emotions related to health, but rather the presence or absence of specific diagnoses (Willison et al. 2009). In fact, there is scant prior evidence in the healthcare literature for differences in consent behavior due to medical problems.

2.2. Role of Emotion in Decision Making

Much of the privacy research to date in IS and health informatics (e.g., Coy 2001, Rohm and Milne 2002, Son and Kim 2008) is based on the tradition that in decision making under risk and uncertainty, people assess the severity and probability of possible outcomes of choice alternatives to arrive at a decision. However, as noted, it is also well documented that emotion has the capacity to alter perceptions, physiology, and abilities (Cosmides and Tooby 2000). Recent influential work by behavioral economists and psychologists indicates that the transformation stimulated by emotion can also influence decision making choices and behavior (Ariely and Loewenstein 2006).

The *risk-as-feelings* perspective (Loewenstein et al. 2001) offers an alternative lens for understanding decision making under risk that incorporates allowances for affective states that do not enter into cognitive evaluations. Such affective states respond to factors that are not typically considered in a rational cognition framework (Loewenstein 2005); for example, emotions are affected by an individual's personal experiences (Weinstein 1989), the vividness of mental images (Damasio 1994), and the timing between the decision and possible outcome (Van Boven et al. 2004). To illustrate, if the individual is anxious or fearful about her medical condition, she might easily be able to visualize a further decline in her health and want to avoid that at all costs (Giordano et al. 2004, Loewenstein 2005). This feeling might dominate any potential privacy concerns she may have.

In addition to having different determinants than cognitive evaluations, emotional reactions are insensitive to probability variations as compared to cognitive evaluations (Loewenstein et al. 2001). For example, people tend to buy insurance more for emotional reasons such as peace of mind than they do based on probabilities (Loewenstein et al. 2001). If an individual is sick, he might disclose information in the hope that it might somehow improve his health, regardless of what the actual probability of improvement may be.

In exploring the role of emotion, Loewenstein (2005) documents what he terms an "empathy gap" in medical decision making. He finds that people have difficulty predicting how they will feel or what they will want if asked to do so for an affective state that is different from their current state (see e.g., Read and Loewenstein 1999, Van Boven and Loewenstein 2003). These gaps take two forms. First, when people are in a "cold" state (i.e., not affectively aroused), they are unable to fully appreciate what their own feelings and behavior will be in a "hot" or affectively aroused state. For instance, people have trouble imagining the motivational force of hunger, pain, or fear and, therefore, underestimate its influence on their feelings and behavior. The reverse is also true. People in a "hot" or affectively aroused state do not realize the extent to which their feelings and behavior are influenced by affect. They tend to believe they are acting more dispassionately then they actually are. Empathy gaps can be further classified as to whether they occur when a person is asked to predict his own behavior in the future (prospective), recall his past behavior (retrospective), or predict the behavior of another (interpersonal).

The existence of empathy gaps is documented in the context of addiction, thirst, pain, and fear (Giordano et al. 2004, Van Boven et al. 2004). In the addiction study, heroin-addicted individuals receiving a methadone-like treatment drug chose between getting a dose of the treatment drug versus different money amounts. They were told that they would receive their choice when they came in for their next treatment five days later. Subjects made their choice either before receiving their drug treatment (currently deprived) for the day, or after. In support of the empathy gap, subjects who were currently deprived better appreciated the force of their future craving and valued the drug treatment more highly than the participants who had already received their treatment and were no longer experiencing a craving. Thus, it is highly plausible that health information privacy decisions are influenced by emotion (i.e., the individual's emotional state related specifically to current health) and that that there exists an empathy gap as well.

3. Conceptual Model

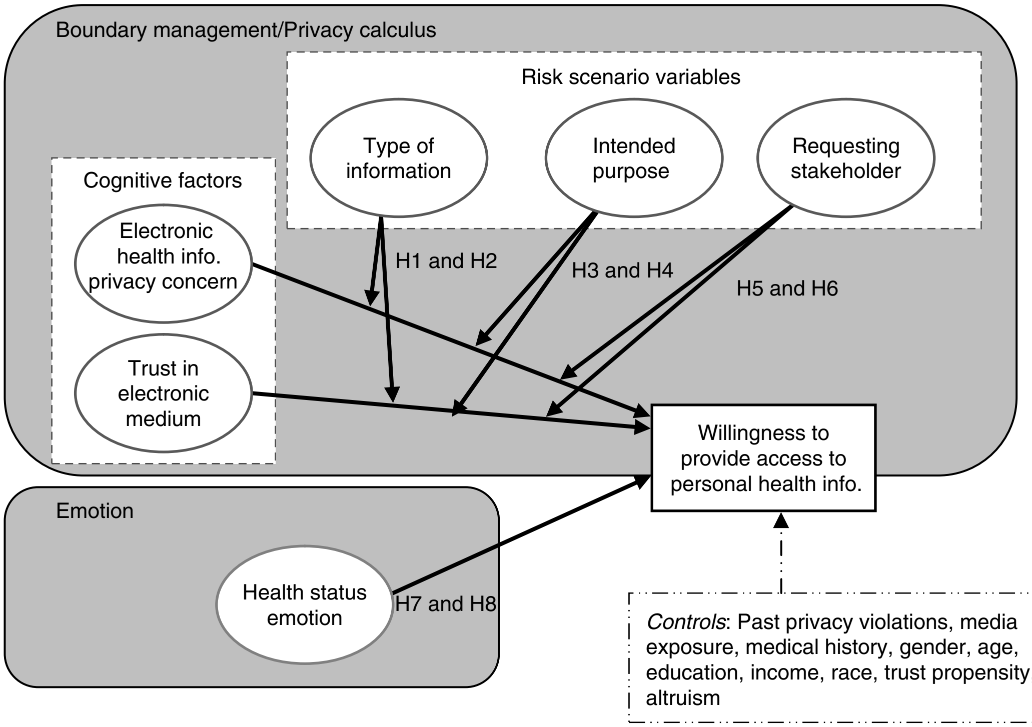
Building on the foundations described above, Figure 1 depicts our conceptualization of the drivers of individuals' willingness to share PHI. The model extends prior work in privacy and health information in two important ways: the inclusion of three moderator variables capturing the information disclosure context in the relationships of the privacy calculus, and the incorporation of emotion as a driver of information disclosure.

The focal dependent variable is individuals' willingness to provide access to a specific type of PHI in electronic format to a particular stakeholder for a specified purpose. Types of PHI can include mental health, general health or genetic information. Healthcare stakeholders are represented by hospitals, pharmaceutical companies, or governmental/public health agencies, each of which has its own interests in obtaining access to consumer PHI (Jha et al. 2009, Kim et al. 2008). PHI could be required in the provision of patient care or be beneficial in facilitating research and marketing products and services. Willingness to disclose information as a condition for transacting is an outcome variable that is consistent with prior privacy research (Malhotra et al. 2004). However, our dependent variable refers to a much more specific outcome, reflecting the contextualization of the theoretical model to the unique healthcare setting.

Consistent with past privacy research in online contexts, we expect to find a negative relationship between an individual's level of privacy concerns regarding the electronic storage of their personal information and their willingness to provide access to PHI (Son and Kim 2008). Prior research has documented this relationship between concern and willingness to disclose extensively; however, as depicted in Figure 1, we suggest that this relationship is more complex than what has been conceptualized previously. In particular, we expect key risk scenario factors to interact with concern in their effects on willingness to disclose health information.

Likewise, as argued in past privacy research that focused on the Internet artifact, we expect to find a positive relationship between an individual's level of trust in the storage of PHI in an electronic format, which is a reflection of the individual's willingness to assume the risks associated with the environment to achieve an outcome, and willingness to provide access to PHI (Dinev and Hart 2006). Our conceptualization of trust is similar to that in Dinev and Hart (2006); it reflects trust in electronic storage as a medium. We view trust as a multi-dimensional construct comprising of competence, reliability, and safety trusting beliefs; i.e., the individual's belief that electronic storage provides a reliable and safe environment in which to store health information, and her belief that the electronic storage format provides the necessary components to facilitate electronic storage of health information. As with concern, while the positive relationship between trust and willingness has been empirically verified in prior work, we expect it to be moderated by the same risk scenario factors that

Figure 1 Conceptual Model



moderate the relationship between concern and willingness to disclose.

Concern and trust represent two key variables that individuals weigh when attempting to balance the costs and benefits involved in privacy disclosure (Dinev and Hart 2006, Gefen 2000). Each is influenced by the boundary management mechanisms that individuals employ, based on the varied risks made salient by the type of PHI requested, the intended purpose of use, and the requesting stakeholder. Previous studies have examined risk and its influence on consumer online behavior in a number of ways, including economic loss as an antecedent to intentions to conduct ecommerce transactions with a particular organization (Jarvenpaa et al. 2000, Pavlou and Gefen 2004), and personal information loss as an antecedent to willingness to disclose to Internet websites in general (Dinev and Hart 2006) and to specific vendors (McKnight et al. 2002). Collectively, these studies suggest that different types of risk might be more influential than others in dissuading individuals from conducting e-commerce transactions (Dinev and Hart 2006). Other research notes that an individual's choice behavior and persuasive propensity differ depending on the domain of risk (Rettinger and Hastie 2001, Mandel 2003). Factors found to influence decision processes across different risk domains such as legal, academic and financial include the personal importance of the outcome, the familiarity with the decision context and moral relevance (Rettinger and Hastie 2001). To the degree that each individual's health status is unique, so is the type of loss perceived as most salient. Thus, all three risk scenario factors could invoke different risk types and levels, influencing the relationships between concern and disclosure and trust and disclosure.

A handful of prior studies have examined the main effect that type of information—such as financial versus purchase preferences (Malhotra et al. 2004) and demographic versus lifestyle (Phelps et al. 2000)—exerts on willingness to disclose, but the more nuanced interaction effect has not been proposed. The notion that some health information is more sensitive than others is supported by the existence of greater legal protection for certain types of health information records (Beckerman et al. 2008, Dimitropoulos 2007); disclosure of information related to mental illness, substance abuse, and even genetic traits can result in negative consequences including social stigma, discrimination, criminal prosecution, and job loss (Beckerman et al. 2008). Drawing on concepts from CPM, individuals likely erect different boundaries around different types of PHI and apply varied rules accordingly. It follows, then, that the degree of influence an individual's privacy concerns regarding the electronic storage of health information in general has on willingness to provide access could vary based on the type of information requested. We expect the increasing sensitivity of the information to amplify the domains of risk that become salient to the individual, thus enhancing the negative influence of concern on willingness to provide access.

Hypothesis 1 (H1). *The type of PHI requested moderates the relationship between concern and willingness to provide access to PHI such that the more sensitive the information is perceived to be, the more negative the relationship between concern and willingness to provide access.*

Dinev and Hart (2006) found perceived Internet privacy risk negatively influenced Internet trust, which suggests a direct relationship between risks and trust in the privacy context. Our risk factors are not directly about the electronic medium but rather, they influence the risks made salient to the individual which, in turn, alter the importance of the relationship between trust and willingness to provide access to information. As the domains of risks made salient to the individual increases with the sensitivity of the type of PHI, so does the importance of trust in the electronic medium.

Hypothesis 2 (H2). *The type of PHI requested moderates the relationship between trust and willingness to provide access to personal health information, such that the more sensitive the information is perceived to be, the more positive the relationship between trust and willingness to provide access to personal health information.*

As noted, a distinctive characteristic of the healthcare context is the multiplicity of stakeholders in the system, each with different domains of activity, organizational goals, and performance criteria. Physicians, hospitals, insurance companies, and pharmaceutical companies all stand to benefit from access to electronic health information for a variety of purposes, including new drug research, trend analysis, marketing, disease outbreak control, and patient care (Jha et al. 2009, Kim et al. 2008). Thus, in a theory aimed at understanding the influence of an individual's health information privacy concerns, it is necessary to consider each of these potential uses of the information to determine if concerns and trust in the electronic medium vary based on the intended use of information. Past information systems privacy research has examined a consumer's concerns related to disclosing information either for the purpose of conducting a business transaction (e.g., Dinev and Hart 2006), to obtain information (Dinev and Hart 2006), or personalized service or advertising (Awad and Krishnan 2006). Findings in the health informatics domain suggest that most individuals want more control over the use of their information when it is for profit-generating purposes (Willison et al. 2009).

Similar to the way the perception of the type of risk varies based on the type of information involved in the risk, the perception of risk type likely varies with the purpose for which the information is to be used. For example, if the request for information is for the provision of care or disease management, the individual might believe that her health is at risk if the information is not provided. This would have to be weighed against any financial and social risks associated with potential unauthorized disclosure of PHI salient in the situation. To the extent that risk-seeking behavior increases as the threat to survival increases (McDermott et al. 2008), individuals tend to be more risk-seeking in situations involving human lives compared to involving money or property (Kühberger et al. 1999, Wang 1996).

Likewise, trust in the electronic medium might become less important in information disclosure decisions when one is fighting for one's life. On the other hand, if the purpose of the request is to use the information for marketing activities, the health benefits are less obvious. Here, potential financial and social risks might become more salient, serving to enhance the negative influence of concern and increase the positive influence of trust on willingness to provide access. The existence of a moderating influence of intended purpose on the concern/willingness and trust/willingness relationships is supported by the work of Awad and Krishnan (2006), who find consumers more willing to share information for personalized service over personalized advertising. Thus, we predict the following:

Hypothesis 3 (H3). *The intended purpose for which PHI will be used moderates the relationship between concern and willingness to provide access, such that the more apparent the potential health benefits are to the individual, the negative relationship between concern and willingness to provide access will be attenuated.*

Hypothesis 4 (H4). *The intended purpose for which PHI will be used moderates the relationship between trust and willingness to provide access, such that the more apparent the potential health benefits are to the individual, the positive relationship between trust and willingness to provide access will be attenuated.*

The third contextual variable relevant to PHI disclosure decisions is the requesting stakeholder. Individuals have varied levels of interaction with and beliefs about the numerous stakeholders involved in the healthcare arena that influence the risks that are made salient when a particular stakeholder requests PHI (Rohm and Milne 2002, Willison et al. 2007). First, while many might see their primary care physicians frequently, they likely visit the hospital less often and correspond directly with pharmaceutical companies or public health agencies even less frequently. Familiarity has been associated with trust (McKnight et al. 2002). If an individual's primary care physician asks for access to PHI for the purposes of conducting research, this might appear less risky than if a pharmaceutical company makes a similar request, because of the level of trust one has for his physician based on a history of interactions. As part of the HISPC initiative, the state of West Virginia conducted a survey of over 500 citizens and validated findings by conducting focus groups (Global Strategy Group 2007). The findings suggest consumers trust doctors and hospitals the most to own electronically stored health information and trust for-profit companies (e.g., insurance companies) the least. The more first-hand knowledge an individual has about a stakeholder, his level of confidence in the stakeholder's expertise and ability to perform as expected should diminish the importance of the role of trust in the electronic medium.

Second, individuals likely have different beliefs about the role different stakeholders should play in the healthcare value chain (Global Strategy Group 2007, Willison et al. 2007). The more consistent the request seems with the organization's overall perceived mission, the less risky it might appear to be to the individual. As noted, because of procedural fairness expectations, individuals are more receptive to requests that appear consistent with the requesting organization's mission (Son and Kim 2008, Stanton 2003). Thus, we test the following hypotheses.

Hypothesis 5 (H5). *The requesting stakeholder moderates the relationship between concern and willingness to provide access to PHI, such that the more trust the individual has in the stakeholder, the negative relationship between concern and willingness to provide access will be attenuated.*

Hypothesis 6 (H6). *The requesting stakeholder moderates the relationship between trust in the electronic medium and willingness to provide access to PHI, such that the more trust the individual has in the stakeholder, the positive relationship between trust and willingness to provide access will be attenuated.*

As noted previously, the benefit side of the privacy calculus typically consists of an assessment of the individual's trusting beliefs, which can balance or offset risks and concerns associated with disclosure (Malhotra et al. 2004). Dinev and Hart (2006) were the first to add a measure for personal interest in obtaining access to content to gauge its influence on willingness to disclose personal information over the Internet. Their findings suggest that personal interest in Internet content can override concerns related to providing information in that context. However, they also point out that research is necessary to further explore the influence of interest in more specific contexts. One important indicator of personal need for health-related information is an individual's health status.

An individual's health is closely tied to emotions, particularly when one is diagnosed with an illness such as cancer or lung disease (Trumbo et al. 2007). These types of medical diagnoses can result in depression (Dalton et al. 2009) and increased anxiety (Trumbo et al. 2007). The influence of emotion in this context has also been documented (e.g., Loewenstein 2005): people make choices in "the heat of the moment" that they might not have made if they had "counted to 10," which suggests the often dominant influence of emotion over cognitive evaluation. The *risk-as-feelings* perspective provides an explanation for individual behaviors that incorporates allowances for emotional influences such as worry, fear, dread or anxiety (Loewenstein et al. 2001).

Loewenstein et al. (2001) propose a distinction between *anticipated* emotions and *anticipatory* emotions. *Anticipatory* emotions are visceral reactions to risks (e.g., fear, anxiety), while *anticipated* emotions are not currently experienced but are expected to be at some point in the future (Loewenstein et al. 2001). The emotion construct in Figure 1 represents the *anticipatory* emotions individuals have involving their health status, as these types of emotions have determinants that are different from those of *anticipated* emotions, which tend to be more cognitive in nature (Loewenstein et al. 2001) and are captured in the concern construct.

Individuals suffering from serious medical conditions often experience visceral, negative emotions related to their health conditions (Trumbo et al. 2007). They have more vivid mental images of the illnesses and their effects on their day-to-day functioning, which disproportionately weighs on decisions related to their health (Loewenstein et al. 2001). Emotions can induce a state of insensitivity to probability variations, which can lead individuals to focus more on the desire to improve their health and feel better when choosing to disclose information, even though the probability of realizing a health improvement is actually lower than the potential privacy risk in disclosing health information (Loewenstein et al. 2001). Finally, people tend to experience increased fear when an outcome is closer to realization, and behaviors can change as a result (Loewenstein et al. 2001). People in a negative mood often make judgments that tend to continue the negativity (Raghunathan and Pham 1999). In the context of one's health, if an individual is sick, it is likely that she will believe she might become sicker and soon need increased care or benefit from research. An otherwise healthy person sees these outcomes (i.e., the necessity for healthcare or research) as far off in the future. In other words, the healthy person is likely to be less influenced by emotion related to his health condition. We therefore predict the following.

Hypothesis 7 (H7). *An individual's negative emotions regarding his/her current medical state negatively* *influence willingness to provide access to PHI. Specifically, the more negative* (*i.e., sad*) *an individual feels about his health, the more willing he is to provide access.*

If emotion is indeed an important factor in the health information privacy context, it is also important to determine if individuals are able to accurately predict the extent to which the emotion might influence their willingness to provide access. Studies have shown that individuals are frequently unable to accurately assess the full impact of emotion on their decision-making ability (Giordano et al. 2004, Van Boven and Loewenstein 2003, Van Boven et al. 2004). In the health setting, the cold-to-hot empathy gap has been suggested as responsible for nonadherence to drug regimens because people who begin to feel better (i.e., are in a "cold" state) do not understand that they might still be sick (e.g., require medication for bipolar disorder) and are unlikely to fully appreciate how bad their condition could get without the medication (i.e., the "hot" state) (Loewenstein 2005). A prospective empathy gap is one that occurs when individuals try to imagine themselves in an emotional state different from their current one and then predict future behavior. If an individual is asked to predict his willingness to disclose under a different emotional state and underestimates the extent to which his decision will be influenced by emotion, this would illustrate the existence of a prospective cold-to-hot empathy gap in the context of health information privacy (Loewenstein 2005). Thus, we test the following.

HYPOTHESIS 8 (H8). *Individuals mispredict the extent to which their emotional state regarding their medical condition influences willingness to provide access to PHI.*

We have theorized that individuals' privacy calculus when deciding whether or not to disclose health information in an electronic storage format (i.e., the main effects of concern and trust) are conditioned by situational risk factors. Such moderating effects have not been theorized or tested before in the health information privacy context. In addition, because of the highly sensitive nature of one's health, we asserted that the decision to disclose health information is influenced by emotion that is difficult for people to accurately predict. The empirical study conducted to test these hypotheses is described next.

4. Methods

4.1. Sample and Data Collection

Our empirical strategy involved a scenario-based repeated-measures quasiexperiment in which subjects are presented with hypothetical scenarios and asked to indicate how they would respond (Rosenthal and Rosnow 1984), an approach commonly used in the marketing literature (e.g., Brady et al. 2005, Rick et al. 2008). The sample for the study is drawn from the target population of the general adult public[2] and specifically constructed to be representative of the U.S. population. In addition, to appropriately test H8, a proportion of the sample is purposefully selected to include a subset of respondents who were diagnosed with cancer. We collected data using an electronic survey administered by a third-party organization based on the demographic characteristics of the sample desired.

The survey provided contextual information on what the digital health exchange of information could look like to ensure that each respondent completed the survey with a common understanding of the core issue. Through a variety of scenarios, each respondent indicated his/her willingness to disclose PHI for three types of information (general, genetic, and mental health), three purposes (marketing, research, and patient care), and three requesting stakeholders (hospital, pharmaceutical company, and government/public health agency), resulting in a total of 27 scenarios (see the online appendix). To eliminate ambiguity, the survey provided explicit definitions and examples of each type of information, purpose of use, and requesting stakeholder. To infuse realism, we adapted scenarios from the HISPC documentation, which has been validated across 33 states and 1 territory (Dimitropoulos 2007).

To test for the existence of an empathy gap in the health privacy context, we developed a hypothetical scenario similar to the ones used in prior empathy gap studies (Giordano et al. 2004, Van Boven and Loewenstein 2003, Read and Loewenstein 1999, Van Boven et al. 2004) (see the online appendix). Unlike the previous scenarios in which only the type of information, requesting stakeholder, and intended purpose were manipulated, in this scenario the individual is asked to imagine that she/he has been diagnosed with colon cancer. The respondent is then asked to indicate his/her willingness to provide health information for the purpose of research using the same scale as in the other scenarios. All respondents received the same hypothetical scenario regardless of whether or not they had cancer.

4.2. Operationalization of Variables

Measures were adapted from prior studies and contextualized for the healthcare setting, and multi-item scales were used to improve reliability and validity of measurement. Willingness to disclose is

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[2] The adult population includes everyone 18 years and older. The provision of health information about minors requires parental consent (Office for Civil Rights (OCR) 2003).

measured using three items on a seven-point semantic scale anchored with unlikely/likely, not probable/probable, and unwilling/willing. We adapted items from Dinev and Hart (2006) to measure trust in electronic storage as a medium for personal health information and electronic health information privacy concern. We utilized 15 items from the Health Emotion Scale (Bowman et al. 2006) to measure anger, disgust, fear, sadness, and joy related to an individual's current health status.[3] This scale, developed to assess primary emotion expressed by physically ill patients, taps into the anticipatory, visceral emotions described by the *risk-as-feelings* literature as opposed to a more thoughtful, reasoned response. The instrument asks respondents to think about how they are currently affected by their health and then to indicate how each item expresses their feelings. Respondents are instructed not to dwell on the statement and to respond immediately.

The survey also captures appropriate demographic variables including age, gender, race/ethnicity, income, and education level. To exclude variance explained by potential confounding factors, we gathered information related to exposure to media coverage of privacy, and prior experience with privacy violations (Malhotra et al. 2004). An individual's altruistic tendencies have been associated with organ donation (Morgan and Miller 2002); therefore, we control for the influence of helping and giving behavior because it could influence information disclosure decisions for research. Because trust in electronic storage as a medium is a central study variable, we also control for an individual's trust propensity (McKnight et al. 2002). Finally, we control for the potential influence of respondents' current medical history by using the number of doctor appointments as a proxy for general overall state of health. See the appendix for all measurement scales. Because of the complex nature of the survey content and its length, we conducted a pilot with 28 respondents to ensure the instructions were adequate and to determine any potential items for elimination. We made minor adjustments to the survey instructions as a result.

5. Results

As with all self-report data, there is the potential for common method bias. We implemented the procedural remedies recommended by Podsakoff et al. (2003) including assuring respondent anonymity, providing contextual information and definitions to reduce ambiguity, and informing respondents that there were no right or wrong answers. We also varied the item scale endpoints and formats between the predictor and criterion measures. In addition, we conducted an exploratory factor analysis as suggested by Podsakoff et al. (2003), which yielded six separate factors (consistent with the number of constructs and controls in the model). No single factor explains the majority of covariance among the measures, indicating that common method biases do not present a significant problem with the data.

The final sample consists of data from 1,089 respondents. The third-party service organization assures an average 20% response rate and does not provide specifics on how many individuals received invitations to participate in the survey. However, because we acquired numerous samples in our efforts to achieve national representativeness and to obtain responses from individuals with cancer, and we were aware of the timing of email reminder notifications, we were able to do subsample comparisons and early/late responder comparisons as recommended by Rogelberg and Stanton (2007). No significant differences were found between the summated scales for the subsamples or early versus late responders, reducing the possibility of nonresponse bias (Rogelberg and Stanton 2007).

Sample demographics closely resemble that of the U.S. population (U.S. Census 2006) in terms of age, education, race/ethnicity, gender, and income distribution (Table 1). Almost half (46.9%) of respondents rate their computer skills as quite extensive or very extensive, which indicates a familiarity with technology. In addition, the average number of years of computer experience is 14.64. Almost one-third of respondents rate their own health as very good or excellent, another third rate it as good, while the remaining third rate their own health as fair or poor, which suggests a broad range of perceived health status. Finally, 313 (28.7%) respondents report having cancer.

Descriptive statistics for the research constructs are shown in Table 2. Cronbach's alpha for the study scales are 0.80 or above, indicating that the measures are reliable. A confirmatory factor analysis performed in SPSS supports the convergent and discriminant validity of the scales (see the online appendix). We created indices for the study variables to be used in the remaining analysis.

5.1. Boundary/Contextual Considerations

We use a repeated-measures ANCOVA analysis to test the influence of type of information, purpose, and requesting stakeholder. This is an appropriate test

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[3] Subjects were presented with roughly equal items to measure positive and negative emotions as Bowman et al. (2006) actually measured eight primary emotions including anticipation, surprise, agreeableness, joy, fear, sadness, anger, and disgust. The agreeableness, anticipation, and surprise items were not included in our analysis due to lack of relevance to our purpose (to examine the impact of negative emotions) and cross loadings during factor analysis.

Table 1 Demographics for Sample and U.S. Population

Demographic characteristic	Sample (%)	U.S. population (%)
Age		
18–24	6.7	Approx. 11†
25–34	13.2	17.5
35–44	17.0	18.9
45–54	21.5	18.8
55–64	18.0	13.7
65–74	14.6	8.2
75 and over	8.4	8.0
Education		
8th grade or less	0.6	6.5
Some school, no degree	1.6	9.4
High school graduate or equivalent	21.2	30.0
Some college, no degree	30.5	19.5
Associate's degree	10.7	7.4
Bachelor's degree	22.1	17.1
Master's degree	8.8	9.9
Doctorate	4.1	
Gender		
Female	56.7	51
Income		
Less than $10,000	6.8	8.0
$10,000 to $14,999	6.6	5.9
$15,000 to $24,999	13.6	11.4
$25,000 to $34,999	16.1	11.2
$35,000 to $49,999	16.5	14.8
$50,000 to $74,999	18.9	19.0
$75,000 to $99,999	9.0	11.8
$100,000 to $149,999	7.0	10.9
$150,000 to $199,999	2.5	3.6
$200,000 or more	2.3	3.4
Race		
White	78.8	73.9
Asian	1.8	4
Black or African-American	13.8	12.4
Native Hawaiian or Other Pacific Islander	0.6	0.001
Other, please specify	4.3	6
Hispanic	11.8	14.8

†The Census reports age breakdowns for 15–19 and 20–25 year olds (i.e., not an 18–24 age range), both of which were 9.2% of the adult population in 2006.

for assessing differences in judgments of the same individuals over a variety of conditions (Potter and Balthazard 2004); it reduces the unsystematic variability in the design by controlling for individual differences, thereby providing greater power to detect effects (Grabe and Westley 2003). We compare an individual's within-subject willingness to provide access to the three types of PHI for three purposes to three different stakeholders. We include electronic health information privacy concern and trust in the electronic storage medium as between subjects factors in the empirical model. To do so, we divide respondents into high and low concern and high and low trust groups based on their scores on the concern and trust indices, respectively.

In addition, we include negative and positive emotion, gender, age, race/ethnicity, income, education, experience with past privacy violations, media exposure, trust propensity, and altruism as covariates in the model. We test for violations of sphericity with Mauchly's test of sphericity. With repeated measures ANCOVA it is important to make adjustments if the variance-covariance matrix of the dependent variables indicates significant differences in variances between conditions (Field 2000, p. 34). We utilized the Greenhouse and Geisser (1959) estimates to obtain a correction factor that assesses the observed F-ratio. Results are reported in Table 3.[4]

The interactions between type of information and concern ($p = 0.277$) and type of information and trust ($p = 0.166$) are not significant. Thus, H1 and H2 are not supported. The data supports two-way interactions (depicted in Figure 2) between purpose and concern ($F_{1.82,1,842} = 9.398; p = 0.000$) and purpose and trust ($F_{1.82,1,842} = 5.825; p = 0.004$). Contrasts indicate that the differences in means between the research and marketing purposes at high and low levels of concern are not significant ($F = 3.391; p = 0.066$). However, the mean levels for the patient care purpose are significantly different from both the research purpose ($F_{1.82,1,842} = 12.774; p = 0.000$) and the marketing purpose ($F_{1.82,1,842} = 14.521; p = 0.000$). The negative relationship between concern and willingness to provide access is attenuated for patient care purposes, supporting H3. When requests are made for marketing or research purposes, the negative relationship between concern and willingness to disclose is enhanced.

Contrasts related to the interaction between purpose and trust indicate that the differences in means between the research and patient care purposes ($F_{1.82,1,842} = 11.306; p = 0.001$) and the research and marketing purposes ($F_{1.82,1,842} = 5.764; p = 0.017$) at high and low levels of concern are significantly different. The means between the patient care purpose and marketing are not significantly different ($F_{1.82,1,842} = 1.450; p = 0.229$). If the request for PHI is made for the purpose of research, individuals with higher levels of trust are more willing to provide access; those with lower levels of trust are less willing to provide access than when the request is made for patient care or marketing purposes. The findings suggest that trust in the electronic medium might be most important in encouraging individuals to disclose information for research purposes. Although the contrasts do not indicate significant differences between patient care

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[4] A fixed effects regression with clustered standard errors to correct for intercorrelations due to multiple observations from the same individual yields results that are consistent with the ANCOVA.

Table 2 Descriptive Statistics

Variable	Reliability (no. of items)	Min	Max	Mean	Std. dev.	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1. Concern	0.88 (3)	1.00	7.00	5.42	1.43	1.00														
2. Trust	0.93 (3)	1.00	7.00	4.57	1.51	−0.06	1.00													
3. Negative emotion	0.95 (12)	1.00	5.00	2.31	1.04	0.14	0.11													
4. Positive emotion	0.80 (3)	1.00	5.00	3.18	1.01	0.13	0.19	−0.18	1.00											
5. Trust propensity	0.91 (3)	1.00	7.00	5.17	1.46	0.19	0.47	0.04	0.21	1.00										
6. Altruism	0.89 (4)	1.00	7.00	5.67	1/05	0.29	0.20	0.03	0.26	0.32	1.08									
7. Willingness to provide access	0.95 (3)	1.00	7.00	4.22	2.07	−0.06	0.45	0.15	0.09	0.28	0.14	1.00								
8. Past privacy violations	n/a	1.00	7.00	3.45	1.73	0.29	−0.11	0.43	−0.04	−0.07	0.04	−0.02	1.00							
9. Media exposure	n/a	1.00	7.00	4.18	1.83	0.27	−0.09	0.21	0.08	−0.03	0.16	−0.07	0.37	1.00						
10. Gender	n/a	0	1.00	0.43	0.50	0.04	0.01†	−0.00†	0.08	0.00†	−0.09	−0.00†	−0.00†	0.06	1.00					
11. Age	n/a	1.00	7.00	4.09	1.68	0.15	−0.02*	−0.12	0.02	0.17	0.20	0.02	−0.18	0.04	0.17	1.00				
12. Hispanic	n/a	0	1.00	0.12	0.322	−0.04	−0.00†	0.03	0.04	−0.03	−0.08	−0.02	0.01*	0.01†	0.02	−0.24	1.00			
13. Race	n/a	1.00	6.00	1.43	1.14	0.00†	−0.03	0.04	0.03	−0.05	−0.05	−0.05	0.06	0.02	0.04	−0.21	0.31	1.00		
14. Income	n/a	1.00	10.00	4.89	2.13	−0.03	0.01†	−0.18	0.16	0.05	0.13	−0.02	−0.05	0.08	0.12	0.06	−0.01*	−0.05	1.00	
15. Education	n/a	1.00	8.00	4.72	1.50	−0.02	−0.06	−0.15	0.02	−0.04	0.03	−0.07	−0.06	0.09	0.15	0.12	−0.02	0.03*	0.37	1.00

*Correlation is significant at the 0.05 level (2-tailed).

†Correlation not significant; all other correlations significant at the 0.01 level (2-tailed).

and marketing at high and low levels of concern, individuals are less willing to provide access for marketing purposes. Due to the decreased significance of the relationship between trust and willingness for patient care compared to research, H4 is supported.

In addition, the data support two-way interactions between stakeholder and concern ($F_{1.97,1,993} = 7.606$; $p = 0.001$) and stakeholder and trust ($F_{1.97,1,993} = 3.301$; $p = 0.038$) (see Figure 3). Contrasts indicate that the mean levels for government/public health agencies are significantly different from both hospitals ($F_{1.97,1,993} = 11.469$; $p = 0.001$) and pharmaceutical companies ($F_{1.97,1,993} = 14.164$; $p = 0.000$) at low and high levels of concern. If the request for PHI comes from a government/public health agency, individuals with higher levels of concern reduce their willingness to disclose, compared to individuals with low concern significantly more than individuals do when the request comes from a hospital or pharmaceutical company. The mean levels of willingness to provide access are not significantly different when the request is made by a hospital or pharmaceutical company ($F_{1.97,1,993}$; $p = 0.620$). Consumers indicate hospitals are among the most trusted stakeholders when it comes to owning and operating electronic health systems, while the government and for-profit organizations are less trusted to take such a role (Global Strategy Group 2007). Due to the enhanced negative relationship between concern and willingness for requests coming from government/public health agencies as compared to hospitals, the data suggest support for H5. The fact that no significant difference exists between hospitals and pharmaceutical companies might suggest that willingness to provide access to PHI is determined not solely based on trust but that other factors related to the perceived role of the stakeholder in the healthcare value chain might also be important considerations.

Contrasts related to the interaction between stakeholder and trust indicate that the differences in means between hospital and pharmaceutical companies ($F_{1.97,1,993} = 4.766$; $p = 0.029$) and hospitals and government/public health agencies ($F_{1.97,1,993} = 4.775$; $p = 0.029$) at high and low levels of concern are significantly different. The means between pharmaceutical companies and government/public health agencies are not significantly different ($F_{1.97,1,993} = 1.997$; $p = 0.158$). If the request for PHI comes from a government/public health agency or pharmaceutical company, individuals with lower levels of trust reduce their willingness to disclose, compared to individuals with high trust, significantly more than when the request comes from a hospital. The positive relationship between trust, and willingness to provide access is attenuated for requests from hospitals, which is consistent with H6.

5.2. Emotion

To determine if there is an influence of emotion on willingness to provide access to PHI, we examine the results of the between-subjects portion of the ANCOVA (see Table 3). Recall that this ANCOVA compares an individual's within subject willingness to provide access to the three types of PHI for

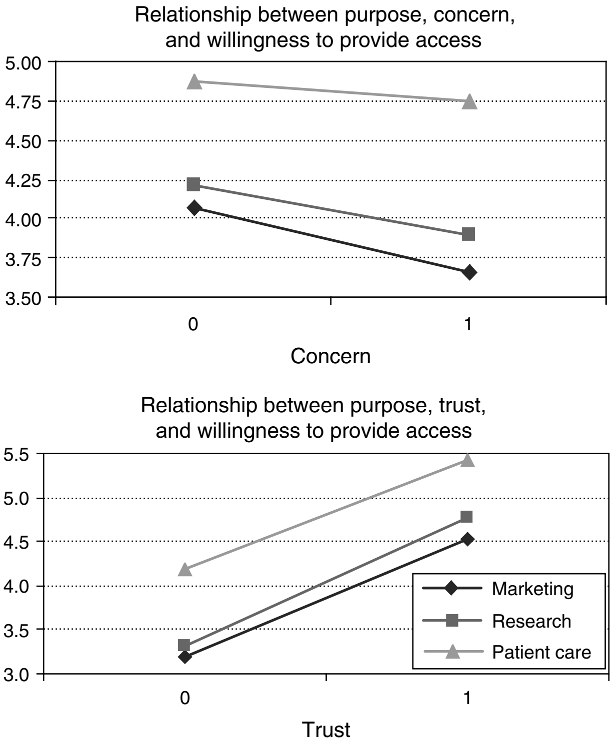
Table 3 **Repeated-Measures ANCOVA Table for Willingness to Provide Access to PHI**

Source of variance	Degrees of freedom*	Mean square	F-statistic*	P-value
Within-subjects factors				
Type	1.59	0.473	0.145	0.816
Type $*$ Concern	1.59	4.134	1.270	0.277
Type $*$ Trust	1.59	6.031	1.852	0.166
Purpose	1.82	51.538	9.916	0.000
Purpose $*$ Concern	1.82	48.845	9.398	0.000
Purpose $*$ Trust	1.82	30.277	5.825	0.004
Stakeholder	1.97	28.869	5.337	0.005
Stakeholder $*$ Concern	1.97	41.142	7.606	0.001
Stakeholder $*$ Trust	1.97	17.857	3.301	0.038
Between-subject factors				
Concern	1	460.887	10.862	0.001
Trust	1	11,401.753	238.702	0.000
Covariates				
Negative emotion	0	1,791.431	42.218	0.000
Positive emotion	0	95.180	2.243	0.135
Altruism	0	320.235	7.547	0.006
Trust propensity	0	1,358.409	32.013	0.000
Medical history	0	6.006	0.142	0.707
Prior privacy violations	0	0.234	0.006	0.941
Media exposure	0	374.234	8.819	0.003
Male	0	15.802	0.372	0.542
Age	0	72.652	1.712	0.191
Hispanic	0	4.786	0.113	0.737
Race	0	105.161	2.478	0.116
Income	0	2.055	0.048	0.826
Education	0	263.058	6.199	0.013
Error(type)	1,012	42.433		
Total N		1,089		
Number of observations per subject		27		
R-squared within		0.20		
R-squared between		0.32		

*The F-statistic violated the sphericity assumption ($p < 0.001$) for each of the within-subject factors. The Greenhouse and Geisser (1959) estimates were applied to make conservative corrections to the F-ratio, which is reported here.

three purposes to three different stakeholders. The items used to assess willingness for this analysis manipulated only the three risk scenario variables and not the individual's health status. Thus, respondents answered these questions with their current health status in mind. As hypothesized, negative emotions are significant ($F_{1,1,012} = 42.218; p = 0.000$) in the model. Individuals who are currently feeling more negative about their health are more willing to provide access to PHI. Positive emotions do not significantly influence willingness ($F_{1,1,012} = 2.243; p = 0.135$). These findings support H7. Of the controls included in the model, altruism and trust propensity significantly increase an individual's willingness to provide access, while higher levels of education and exposure to media reports about use and potential misuse of health information decrease willingness.

Figure 2 **Purpose Interaction Graphs**



Our final analysis related to the role of emotion in PHI disclosure involved assessing the potential existence of an empathy gap in the context of privacy. Following past empathy gap research, we asked each

Figure 3 **Stakeholder Interaction Graphs**

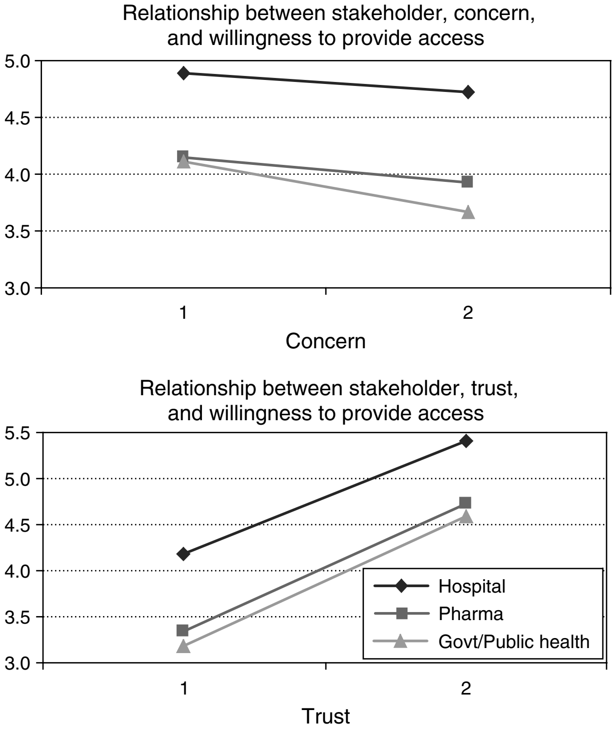


Table 4 Results by Hypothesis

Hypothesis	Support?
H1: Type of Health Information ∗ Electronic Health Information Privacy Concern → Willingness to Provide Access to PHI	No
H2: Type of Health Information ∗ Trust in Electronic Medium → Willingness to Provide Access to PHI	No
H3: Intended Purpose ∗ Electronic Health Information Privacy Concern → Willingness to Provide Access to PHI	Yes
H4: Intended Purpose ∗ Trust in Electronic Medium → Willingness to Provide Access to PHI	Yes
H5: Requesting Stakeholder ∗ Electronic Health Information Privacy Concern → Willingness to Provide Access to PHI	Yes
H6: Requesting Stakeholder ∗ Trust in Electronic Medium → Willingness to Disclose	Yes
H7: Health Status Emotion → Willingness to Provide Access to PHI	Yes
H8: Differences in Willingness to Provide Access to PHI for Research between Respondents with and Without Cancer (Empathy Gap)	Yes

respondent to read a hypothetical scenario requiring the respondents to imagine themselves in a state that is evoking emotion (i.e., being diagnosed with colon cancer) and then indicate their willingness to provide access to their PHI to a pharmaceutical company for clinical trial research (Read and Loewenstein 1999, Van Boven et al. 2004). The hypothetical scenario was administered to all respondents. To determine if an empathy gap exists, comparisons are generally made between respondents in a state that is emotionally similar to the hypothetical scenario (i.e., respondents with any form of cancer) and respondents who are not in such a state (i.e., do not have cancer) (Read and Loewenstein 1999, Van Boven et al. 2004). For our purposes, we compare willingness to provide access to PHI in a hypothetical "cancer-diagnosis" scenario (see online appendix) between respondents in our sample who currently have cancer and those who are cancer-free. A cancer diagnosis is associated with a variety of negative emotions, including anxiety and depression (Trumbo et al. 2007), and is considered a "hot state." These two groups vary significantly in their levels of positive and negative emotions. The cancer group has significantly higher levels ($F_{1,1,018} = 16.975$; $p = 0.000$) of negative emotion ($M = 2.520$) compared to the cancer-free group ($M = 2.225$) and significantly lower ($F_{1,1,018} = 6.041$; $p = 0.014$) positive levels ($M = 3.061$) of emotion compared to the cancer-free group ($M = 3.232$), which supports the notion that the cancer group is in a "hot state."

An ANCOVA comparing responses between the two groups indicates that people who have cancer show a significantly higher ($F_{1,1,015} = 7.171$; $p = 0.008$) willingness to provide access to PHI (Mean = 5.370) to pharmaceutical companies for clinical trial research if they were hypothetically diagnosed with cancer than people who do not currently have cancer (Mean = 5.060). This suggests that people are unable to accurately predict how the emotion associated with a cancer diagnosis might influence their privacy decisions, because people who *do not* have cancer indicate a significantly lower willingness when compared to those who do. We controlled for individual level factors such as gender, age, education, income, race/ethnicity, media exposure, prior privacy violations, altruism, trust propensity, electronic health information privacy concern, and trust in the electronic medium. Hypothesis 8 is supported. Table 4 summarizes the results for all hypotheses.

5.3. Discussion

Overall, empirical results support six of the eight hypotheses and collectively suggest that contextual factors related to the requesting stakeholder and the purpose for which the information is being requested play an important role in moderating the relationships of the privacy calculus, i.e., the effects of concern and trust on willingness to provide access to PHI. As theorized, individuals erect boundaries around their electronic PHI and apply different rules to determine whether or not to disclose their PHI depending on the risk domains made salient by the factors relevant in the healthcare context (Global Strategy Group 2007, Willison et al. 2009). Furthermore, we find evidence that emotion plays a pivotal role in PHI disclosure: individuals with negative emotions involving their current health status are more willing to disclose PHI. Individuals are also unable to fully comprehend the extent to which a negative diagnosis and the associated emotion might influence their privacy decisions.

Our predictions related to the moderating effect of type of information requested in the privacy calculus were not supported. Not only does type of information not moderate the relationships, we find that type of information does not have a significant main effect on willingness to provide access to PHI. We explored a post hoc explanation that perhaps the interaction of type of information with concern and trust would significant be only for individuals who have been sensitized to be concerned about a particular type of information (e.g., mental health). Analyses to determine if respondents who indicated they are suffering from depression (i.e., have a mental health issue) exhibit different results based on type of information revealed that the "type of information" interactions remain insignificant for this group of "sensitized" individuals. Our expectation for moderation was predicated on the argument that different types of health information are differentially sensitive and could result in varied levels of loss, hence, risk. Although counter-intuitive at first glance, and inconsistent with prior work that has found differences across, for example, financial and purchase information (Malhotra et al. 2004), a plausible explanation for this is that *all* types of health information are sensitive (Kam and Chismar 2006, Rohm and Milne 2002). It might be the case that individuals do not distinguish between different types of health information and believe that the entire set represents the same level of privacy risk, thereby rendering the main effect of type of information insignificant. This explanation merits further investigation by examining, for example, health and financial information in the same study.

5.4. Limitations

Prior to discussing the implications of our findings, limitations of the study that also suggest useful directions for future research deserve consideration. Although our sample closely matched the U.S. census demographics, which improves the ability to generalize findings to the U.S. population, the survey was administered online, and therefore respondents represent individuals who have access to an Internet-accessible computer. Future studies should include hardcopy survey and/or telephone interview methods to reach individuals who might not have access to computers as their concerns, trust, and willingness to disclose in a digital environment might be different from individuals with more experience with such environments. A second limitation relates to our measurement of intentions as opposed to actual behavior. Intentions have been shown to be a strong predictor of actual behavior (Webb and Sheeran 2006) and also have also been commonly used as a proxy for actual behavior in information privacy studies (Malhotra et al. 2004, Son and Kim 2008). Although a fruitful avenue for future study is to pursue methods that enable examination of consumer privacy behavior in healthcare settings, at this time it is not feasible to realistically design a study to accurately assess the actual behavior of interest to our research questions. Our study was intended as an initial step toward gauging consumer concerns and the factors influencing disclosure in a reality where the consumer has expanded control over the access and use of their own PHI. As such, our scenarios involved an element of forward thinking.

Although we endeavored to examine risk-specific variables such as type of information and purpose of use to gain a more granular understanding of privacy concerns, our stakeholder manipulation remained at a general level (e.g., nonspecific hospital, pharmaceutical company). It does not enable us to address concerns individuals might have related to specific entities such as the Veterans Administration, Pfizer, or the Mayo Clinic. Other studies have examined the role of vendor reputation (McKnight et al. 2002) or familiarity (Gefen 2000) as they relate to intentions to perform Internet transactions, which was not the focus of our study. By focusing on the stakeholder in general, our research design eliminated the potential influence of particular entities, thus emphasizing the category of the stakeholder. We suggest that both the category of the stakeholder in general and perceptions related to the specific stakeholder (e.g., XYX Memorial Hospital) are important for understanding user behavior, and more research is necessary to understand the mutual influence of these factors.

As is a potential concern with any repeated measures design, our results might reflect the influence of order effects. In our study respondents had to read and respond to 27 scenarios that were consistently administered to all. Counterbalancing the ordering of questions is one technique for avoiding systematic order effects with a small number of conditions, but it quickly gets difficult to manage as the number of possible combinations increases and was, therefore, infeasible in our case. Indeed, counterbalancing and randomizing conditions do not always control for order effects and should be used in cases where there is reason to believe the effects are significant enough to subsume or inflate the treatment effects (Cohen 1995, Reese 1997). Moreover, we do not have reason to believe that any group of interest in our study (e.g., low/high concern or low/high trust) is any more sensitive to carryover effects (e.g., practice, fatigue, contrast, or assimilation) than any other, which suggests our approach of administering scenarios consistently is reasonable (Cohen 1995).

We conducted our research with individuals living in the United States, which has its own cultural beliefs regarding privacy, privacy policies, and legal structure. Whether or not our findings generalize to other countries is an empirical question for future research. Our findings might generalize to other countries with privacy policies and associated legal structures similar to the United States. However, privacy policies in other parts of the world, such as the European Union, are more stringent and rigorous than in the United States. For example, experts indicate that individuals in the European Union are provided with more choice and consent regarding how their information is used and shared, and compliance with privacy policies is more strictly monitored (Cline 2006). In an environment in which the individual has more choice and greater protection overall, it might be that the influence of varied contextual factors is less pronounced.

Finally, our findings suggest that an empathy gap exists in the health information privacy context. We would expect an empathy gap to exist for purposes directly related to a person's health status (e.g., patient care or research but not necessarily marketing) because affect related to a person's health status can change over time based on an improvement or degradation of health status. In addition, we would expect the results to generalize to other stakeholders as long as the individual believes the stakeholder could effect change on the individual's health status. A fruitful avenue for future research could be to explore the limits to the empathy gap in the context of disclosure of private information.

6. Implications and Conclusion

There is little else as consequential to an individual as his or her own health. As healthcare becomes increasingly digitized, the promise of improvements enabled by technological advances must inevitably be traded off against any unintended negative consequences. There is much value to be realized in drug discovery, medical research, and public health policy if consumers are willing to allow their health information to be electronically stored and manipulated (Lunshof et al. 2008). We asked a question that must be answered in order to craft appropriate policy and encourage usage of HIT in the future: under what circumstances will individuals be willing to disclose PHI and allow it to be digitized?

In this study we noted that healthcare affords an optimal setting to study privacy concerns for multiple reasons, including the highly sensitive nature of different components of health information and the number of stakeholders with a vested interest in gaining access to consumer health information for a variety of purposes. The nature of risks related to the discloser of health information is diverse (Beckerman et al. 2008). In addition, as is less the case in retail or in financial settings in which much prior privacy research has been conducted (e.g., Dinev and Hart 2006), an individual's health status involves strong emotion (Trumbo et al. 2007), which can influence decision making (Loewenstein 2005). We discuss the theoretical and practical implications of our findings.

6.1. Theoretical Implications

The study's contributions extend to both the general privacy discourse (the role of emotions and the situational nature of privacy concerns) and the specific instance of healthcare information (which is where our study is firmly anchored in its detailed operationalization of "situation" and the measures used). The study contributes to theory in several ways. First, we introduced and reasoned about the moderating influence of three situational risk factors (type of information, intended purpose, and requesting stakeholder) on the relationships between concern and willingness to disclose PHI and trust and willingness to disclose. Concern and trust represent the core relationships in the privacy calculus (Culnan and Bies 2003, Dinev and Hart 2006, Malhotra et al. 2004, Mayer et al. 1995). Second, we explicitly incorporated emotion into the privacy calculus. Third, we specifically examined risk-factor moderating variables and health status emotion, which are customized for the healthcare context.

Previous privacy research has focused on either of the two situational risk factors at one time, such as willingness to disclose information for the purposes of personalization (Awad and Krishnan 2006), or to disclose in order to obtain a service (Dinev and Hart 2006), or to disclose to a particular fictitious vendor (Malhotra et al. 2004); or has focused on the main effects of vendor reputations or familiarity (Gefen 2000, McKnight et al. 2002). We extend this literature by examining the more nuanced interactive influences of situational risk factors on the core privacy calculus relationships. Our model provides a framework for understanding which factors influence individual beliefs about the use of a general technical format (i.e., electronic storage) in a specific context (i.e., healthcare). Although the healthcare context, with its multiplicity of stakeholders and their distinct objectives, provided a fertile setting in which to perform initial tests of these relationships, future investigations could explore whether or not these relationships hold in financial or purchase history contexts.

Although the majority of research on judgment and decision making is cognitive and consequentialist in nature (Harless and Camerer 1994, Tversky and Kahnemann 1984, Vroom 1964), the role of emotion is beginning to be acknowledged in domains outside of information privacy (Ariely and Loewenstein 2006, Druckman and McDermott 2008, Loewenstein et al. 2001). To our knowledge, this study is the first to incorporate emotion into the privacy calculus. We focused on anticipatory emotions, which are immediate visceral reactions because they tend to have different determinants than those that drive cognitive evaluations (Loewenstein et al. 2001). It was our belief that the healthcare context provided an extreme case in which to observe the relationship between emotion and willingness to provide access to information (Druckman and McDermott 2008, McDermott et al. 2008). Future studies could explore this relationship in other privacy settings such as the financial context. In addition, because emotion is linked with physiology, future studies could attempt to measure privacy concerns in clinical settings and, perhaps, obtain physiological measurements from the clinician in addition to the patient self-reported emotions.

Given that emotion is a factor in an individual's willingness to disclose PHI, interesting avenues for future research include determining the boundary conditions for this relationship as well as the potential influence of emotion on the cognitive aspects of the model. In terms of boundary conditions for the influence of emotion on disclosure, does the health status of a close loved one (e.g., a child, parent, or spouse) and the subsequent related emotion influence an individual's willingness to provide access to PHI for clinical trial research? Similarly, it seems plausible that altruism could play a stronger role in influencing the willingness to disclose for the purpose of research than for the purpose of one's own care, which represents an interesting question to study. In regard to the influence of emotion on the cognitive aspects of the model, future research could examine the potential influence of emotion on the trust/willingness and concern/willingness relationships. It is possible that emotion interacts with the cognitive aspects of the model; however, we focused on anticipatory emotion (i.e., emotion eliciting a visceral reaction). Anticipatory emotions have different determinants, such as immediacy of risk and vividness, which do not influence the cognitive evaluation process in the same manner. These types of emotions are suggested as having a direct influence on behavior/decisions. Anticipated emotions (emotions not experienced at the present time but expected to be experienced in the future) are factored into the cognitive evaluation of decision outcomes. We did not manipulate or assess anticipated emotions.

Other areas for future exploration involve the role of financial and social incentives, which might be viewed as extensions to the privacy calculus. In addition to the potential benefits the individual perceives as inherent in requests for access to PHI for patient care, research, or marketing, organizations could increase the benefits by providing individuals with monetary rewards in exchange for access to their information. However, studies have suggested that individuals are somewhat unwilling to sell their information to websites (Hoffman et al. 1999, Ward et al. 2005). It might be that a combination of monetary incentives and interactions that form a social exchange contract (e.g., newsletters sharing research findings) are most effective at increasing individual willingness to provide access to PHI (Ward et al. 2005).

6.2. Practical Implications

As we move forward toward a goal of electronic health records for all U.S. citizens by 2014, it is essential to understand what roadblocks stand in the way of progress and to understand the ramifications of such progress. The practical implications of the study include an improved understanding of consumer concerns regarding the electronic storage of health information. A particularly striking result is the finding related to the influence of negative emotion on individual willingness to disclose PHI. Individuals who feel sad, angry, and anxious about their current health status are more willing to provide access to their PHI and are thus more vulnerable to opportunistic requests for their information. However, people in an unemotional state might feel strongly that they don't want to be a "lab rat" or "guinea pig" until it is their own life at stake, in which case the emotion involved with facing their own death influences their decision in a direction that might benefit that individual. At a societal level, the findings related to emotion and the empathy gap in the health information privacy context raise difficult questions about the timing of consent, which has important policy implications. If people's judgments vary with their emotions related to their health at a given point in time, should consent be sought at every interaction with a healthcare professional? If an individual is unduly influenced by emotion, he or she might make a decision he or she might regret at a later time, at which point the damage could already be done if private information has already been disclosed to an unintended entity (Loewenstein 2005). Thus, at the individual level, an acknowledgement of the influence of emotion in the privacy calculus might help individuals become aware of and minimize its influence on their behavior.

It is unsurprising that our findings indicate consumers are most willing to share information with hospitals and for the purpose of patient care. However, significant benefits stand to be gained from the digitization of health information for research and it is unlikely that all of that research can be conducted by hospitals. Our findings suggest the need for more assurance of privacy and trust built in governmental agencies and pharmaceutical companies before consumers become comfortable with sharing information with such stakeholders. More research might be required to understand why consumers seem particularly concerned about sharing information with the government/public health agencies as opposed to hospitals and pharmaceutical companies. Given the variation in willingness to disclose to different stakeholders, we cannot assume we know what consumers want. Rather, the consumer should have more control over the flow of their personal information (Noblin 2007, Simon et al. 2009). Currently, HIPAA enables the patient to access their own record and to authorize disclosure of records to third parties.

However, the authorization does not mandate disclosure (Bernstein et al. 2008). If an individual wants his/her information shared, the information should be released as appropriate. Our findings further suggest that part of HIPAA regulation should be that requesting stakeholders have to clearly identify who they are and what the information will be used for (Gostin and Nass 2009). We note that the boundaries erected by individuals might change over time as the individual's awareness levels associated with the boundary variables (purpose, type, stakeholder) evolve. For example, if individual perceptions of trust in various stakeholders change based on public relations/marketing efforts or levels of interaction, that would influence the role of requesting stakeholder. Therefore, the consent granted by individuals should be valid only for a specific time period, given that health status emotion and boundaries can change over time.

In addition, consumers stand to gain from appropriate research efforts and marketing campaigns if conducted in a way that is sensitive to their needs. Relatedly, a striking finding revealed that trust in the electronic medium is more important when a request is made for research purposes than when a request is made for marketing or patient care purposes. Perhaps this reflects an underlying negative bias toward participation in research, a supposition that warrants more study.

Although not a primary goal of this study, we explore potential implications for the design for technological artifacts for storing PHI and associated privacy protection technologies. Studies consistently note that the average consumer has a limited understanding of underlying technical complexities involved in securing digital information (e.g., Furnell et al. 2007, Jensen et al. 2005, Porter 2009). Perceptions of the relative security of one type of technology over another (e.g., a portable mass storage device versus a repository on a centralized server) are often constructed on the basis of anecdotal information that may not reflect the true capabilities of the artifact, and are grounded in the assurances provided with the system rather than the technology itself. Furthermore, as discussed by Lunshof et al. (2008), it is theoretically not possible for medical researchers and scientists to offer absolute guarantees related to health information privacy simply because there is no system that is fool-proof. Arcane methods for protecting privacy, such as k-anonymization algorithms, are incomprehensible for the average consumer. Thus, we would suggest that as the privacy debate continues to unfold, the precise nature of the underlying technology is likely to be a less important consideration for individuals compared with the safeguards and protection that are bundled around it.

6.3. Conclusion

The objective of this study was to shed light on a vexing problem facing the healthcare industry with respect to digitization: escalating privacy concerns about personal health information. Drawing upon privacy boundary theory and the risk-as-feelings perspective we sought to gain a broad-based understanding of individuals' privacy calculus in the healthcare context. Our theoretical model simultaneously examined a broad range of contextual variables that might influence the risks that become salient to an individual. It further incorporated a hitherto overlooked determinant of information disclosure decisions that is arguably of especial significance in healthcare, viz., emotion. We proposed the existence of an empathy gap in PHI disclosure decisions, suggesting that individuals cannot accurately predict how their privacy decisions will change over time. Data from a nationally representative sample of over 1,000 adults support our core assertions and provide evidence for the complex nature of consumer health information privacy concerns. The results have both theoretical and practical implications. Policy makers can use this information to craft policies tailored to meet consumer needs. In addition, consumers can be segmented into groups for targeted marketing campaigns designed to, for example, either recruit consumers who are particularly open to sharing information for potential participation in clinical trials or educate particularly resistant consumers on the benefits and safety of electronic health records.

7. Electronic Companion

An electronic companion to this paper is available as part of the online version that can be found at http://isr.journal.informs.org/.

Appendix

Controls

Past privacy violations: How frequently have you personally been the victim of what you felt was an improper invasion of privacy? (1 = very infrequently; 7 = very frequently)
Very infrequently 1–2–3–4–5–6–7 Very frequently
Media exposure: How much have you heard or read during the last year about the use and potential misuse of health information collected electronically? (1 = not at all; 7 = very much)
Not at all 1–2–3–4–5–6–7 Very much
Computer experience: How many years of experience do you have using computers?

How would you rate your *computer skills*?

- ☐ 1 None
- ☐ 2 Very little
- ☐ 3 Average
- ☐ 4 Quite extensive
- ☐ 5 Very extensive

Table A.1 Measurement Items[a]

Construct	Measure
WILLING1[b]	Unlikely/Likely
WILLING2	Not Probable/Probably
WILLING3	Unwilling/Willing
TRUST1	The electronic/digital storage format of health information is a safe environment in which to exchange health information with others
TRUST2	The digital storage format is a reliable environment in which to conduct health related transactions
TRUST3	Organizations handle personal health information submitted by patients in an electronic format in a competent fashion
CONCERN1	Compared with other subjects on my mind, the privacy of my electronic personal health information is very important
CONCERN2	I am concerned about threats to the privacy of my electronically stored personal health information today
CONCERN3	All things considered, I believe the privacy of my electronic personal health information is seriously threatened
NEGEMOT1	Right now I feel sad about something that has happened to my health
NEGEMOT2	I feel disgust for my current state of health
NEGEMOT3	I have an intense loathing for my present state of health
NEGEMOT4	I feel furious at my present state of health
NEGEMOT5	I feel very deep sorrow because of my health
NEGEMOT6	Right now other things in my life will have to wait
NEGEMOT7	My current health state is a real inconvenience
NEGEMOT8	I am extremely displeased with my present health state
NEGEMOT9	Health problems are tiresome to me
NEGEMO10	My present health problems fill me with dread
NEGEMO11	Recent experience has warned me to be more cautious about my health
NEGEMO12	I feel everything needs to be approached with caution right now
JOY1	My spirits are high today
JOY2	I feel ecstatic about life right now
JOY3	I am happy about my health right now
ALT1	Helping others is one of the most important aspects of life
ALT2	I enjoy working for the welfare of others
ALT3	My family tends to do what we can to help those less fortunate than ourselves.
ALT4	I agree with the old saying, “It is better to give than to receive”
TP1	I usually trust people until they give me a reason not to trust them
TP2	I usually give people the benefit of the doubt
TP3	My general approach is to trust new acquaintances until they prove I should not trust them

[a] Full instrument is available from the authors.

[b] More detail regarding the measurement of Willingness to Disclose PHI is provided in the online appendix because the wording changed for each of the 27 combinations of type of information (3), requesting stakeholder (3), and purpose of use (3) for which willingness was captured.

How frequently do you schedule *doctor appointments* for yourself?

- ☐ 1 More than once a month
- ☐ 2 Every 1 to 2 months
- ☐ 3 Every 3 to 6 months
- ☐ 4 Every 7 to 12 months
- ☐ 5 Less than once a year

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