



PRIVACY RISKS, EMOTION, AND CONSUMERS' WILLINGNESS TO SHARE PERSONAL HEALTH INFORMATION

Catherine Anderson, *Ph.D. Candidate, Robert H. Smith School of Business*

Ritu Agarwal, *Professor and Robert H. Smith Dean's Chair of Information Systems and Director of CHIDS*

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."

New York Times, January 17, 2009

Today's public 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 where IT enables the practice and delivery of medicine to be increasingly personalized, in much the same way as products and services are customized to the needs and preferences of consumers in commercial domains. Simultaneously, it has ignited unprecedented concerns regarding the protection of large quantities of personal information that must be captured in electronic health records, which provide the foundational technology platform for interoperability and the realization of promised benefits. As the volume of information which is potentially vulnerable increases exponentially, so does the urgency of finding appropriate policies to protect consumer privacy, while reaping the benefits of digitization.

On the surface, it may appear that the healthcare context is similar to other privacy dilemmas in which individuals evaluate the costs and benefits of disclosing personal information. However, the healthcare context is unique in many respects because of the variety of risks raised with the potential privacy loss of sensitive health information as well as the emotion linked to one's medical state.

We conducted a study to examine consumers' willingness to disclose personal health information (PHI) so that it may be digitized and potentially shared with others. We collected data from a nationally representative sample of over 1000 consumers. This research brief discusses the

key findings of the study.

The Complex Privacy Calculus for Personal Health Information

The decision related to allowing PHI to be digitized is not a simple one. It is likely 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. 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 due to their sensitive nature. Further, the healthcare value chain has multiple players with a need to access and use PHI, and the individual has varied degrees and methods of interaction with these organizations. Finally, a key contextual consideration is the purpose for which information will be used. How do individuals make choices in such a complex contextual milieu? To answer this question we draw from Communication Privacy Management (CPM) theory which, in conjunction with the healthcare context, provides insight into potential risk factors which influence an individual's level of concern and trust (i.e. the privacy calculus).

A second element of complexity in healthcare decisions is the emotion associated with them. Increasingly studies show that emotions have a profound influence on decisions, yet surprisingly privacy research has yet to incorporate emotion in its theorizing. In terms of health status, medical condition (e.g. pain, addiction, fear) has been shown to alter preferences and behavior. Previous studies have also suggested that individuals mis-predict their response in situations where emotions play a significant role. We combined these factors into the conceptual model shown in Figure 1.

The focal dependent variable is an individuals' willingness to share a specific type of PHI in electronic format with a particular stakeholder for a specified purpose. Types of PHI in the study include mental health, general health or genetic information. Healthcare stakeholders are represented by hospitals, pharmaceutical companies or governmental/public health agencies. PHI may be required in the provision of patient care, to facilitate research, or be beneficial in the marketing of products and services.

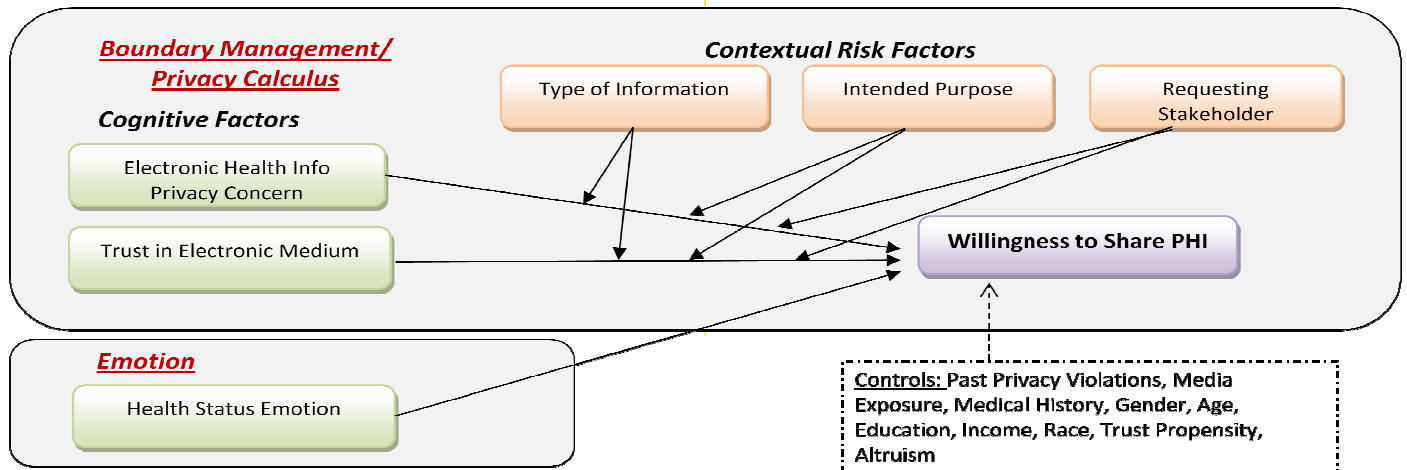


Figure 1. A Model of Consumer Digitized PHI Concerns

An individual’s health is closely tied to emotions, particularly when one is diagnosed with a serious illness such as cancer or lung disease. These types of medical outcomes can result in depression and increased anxiety. The emotion construct in Figure 1 represents the emotions individuals have involving their health status that are visceral reactions to risk (e.g. fear, anxiety). When individuals have more vivid mental images of their illnesses, it may disproportionately weigh on decisions related to their health.

The Study

We collected data using an electronic survey administered by a third party organization. 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 percent) 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 1/3 of respondents rate their own health as very good or excellent, another third rates it good while the remaining third rates their own health as fair or poor which suggests a broad range of perceived health status. Finally, 313 (28.7%) respondents report having cancer.

The survey provided contextual information on what the digital health exchange of information could look like. Through a variety of scenarios, each respondent indicated his/her willingness to share 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. To test for the existence of an

empathy gap in the health privacy context, we developed a hypothetical scenario. In this scenario, the individual is asked to imagine that s/he has been diagnosed with cancer. The respondent is then asked to indicate his/her willingness to share health information for the purpose of research using the same scale as in the other scenarios.

Race	Sample	U.S. Population
White	78.8%	73.9%
Asian	1.8%	4.0%
Black or African American	13.8%	12.4%
Native Hawaiian or Other Pacific Islander	0.6%	0.001%
Other, Please Specify	4.3%	6.0%
Hispanic	11.8%	14.8%

We used a repeated measures ANCOVA analysis to test the influence of type of information, purpose and requesting stakeholder. The data show significant interactions between purpose and concern, and purpose and trust. In addition, we found significant interactions between stakeholder and concern and stakeholder and trust. The interpretations of these findings are as follows. In general, we expect an individual’s level of privacy concerns regarding the electronic storage of their PHI to lower their willingness to share PHI. However, we found concerns about electronic health information privacy played more of a negative role in the disclosure decision for marketing or research purposes than it did for patient care purposes.

Trust in the electronic medium generally increases an individual's willingness to disclose. Our findings indicate that when the request for PHI is made for the purpose of research, individuals with higher levels of trust are more willing to provide access and those with lower levels of trust are less willing to provide access than when the request is made for patient care or marketing purposes. This suggests that trust in the electronic medium might be most important in encouraging individuals to share information for research purposes. Overall, individuals were least willing to share for marketing purposes.

An illustrative interaction for stakeholder and concern is shown in Figure 2. As mentioned previously, we expect higher levels of concern to lower willingness to share.

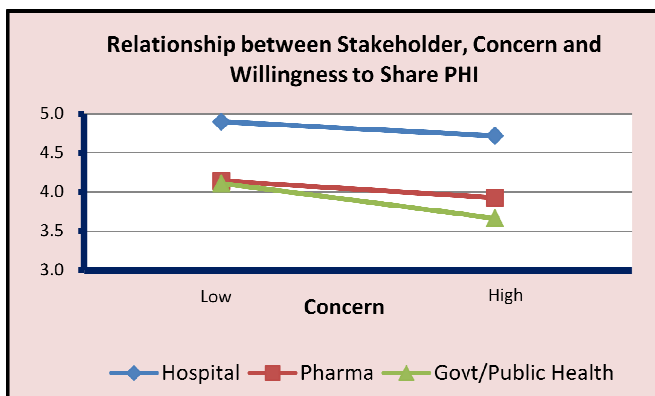


Figure 2. Interaction Between Stakeholder and Concern

However, 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 share PHI are not significantly different when the request is made by a hospital or pharmaceutical company.

Finally, the interaction between stakeholder and trust indicates that trust in the electronic medium is more important when the request for PHI comes from a pharmaceutical company or government/public health agency as opposed to a hospital.

To test for evidence relating to the existence of an empathy gap in the context of privacy, we used the responses to the hypothetical cancer diagnosis scenario. We compared responses for two groups: a cancer-free group and a group indicating later in the demographic section of the survey that they currently have cancer. The

cancer group had significantly higher levels ($F=16.975$; $p=.000$) of negative emotion ($M=2.520$) as compared to the cancer-free group ($M=2.225$) and significantly lower ($F=6.041$; $p=.014$) positive levels of emotion as compared to the cancer-free group which supports the assumption that the cancer group is in a different affective state than the cancer-free group.

As shown in Figure 3, individuals currently experiencing highly negative emotions about their health condition are generally more willing to share PHI. An ANCOVA comparing responses between the two groups indicates people who have cancer indicate a significantly higher willingness to share PHI ($M=5.370$) with pharmaceutical companies for clinical trial research if they were hypothetically diagnosed with cancer than people who do not currently have cancer ($M= 5.060$). This suggests that people who have cancer are better able to imagine what a cancer diagnosis feels like and how it might influence their decision making processes. Moreover, the findings suggest that people are unable to accurately predict how the emotion associated with a cancer diagnosis may influence their privacy decisions since people who do not have cancer indicate a significantly lower willingness to disclose PHI when compared to those who do.

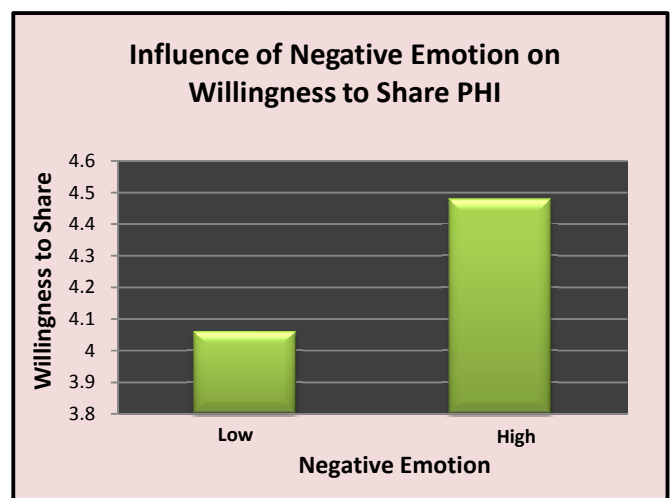


Figure 3. Negative Health Status Emotion

Discussion

Our analyses reveal a number of intriguing findings. A particularly striking result relates to the influence of negative emotion on individual willingness to share PHI. Individuals who feel sad, angry and anxious about their current health status are more willing to share their PHI and are, thus, more vulnerable to opportunistic requests for their information. However, people in an unemotional state may 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 may benefit that individual. Individuals are also unable to fully comprehend the extent to which a negative diagnosis and the associated emotion may influence their privacy decisions. This is termed an "empathy gap". At a societal level, the findings related to emotion and the empathy gap in the health information privacy context, create difficult questions about the timing of consent which has very real policy implications. If people's judgments may 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, they may make a decision which they may regret at a later point in time at which point the damage could already be done if private information has already been disclosed to an unintended entity. An acknowledgement of the influence of emotion in the privacy calculus may help individuals become aware of and minimize its influence on their behavior.

Our findings also indicate that situational factors strongly influence consumer willingness to disclose PHI. Consumers appear to be particularly concerned about sharing information with the government/ public health agencies as opposed to hospitals and pharmaceutical companies. 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 individuals have in regard to participation in research, a supposition that warrants more study. It is unsurprising that our findings also 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 that there may need to be more assurance of privacy and trust built in governmental agencies and pharmaceutical companies before consumers become comfortable with sharing information with such stakeholders.

Conclusion

There is little else that is 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 that can 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. Policy makers can use the findings of this study 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.

Suggested Citation:

Anderson, C. and Agarwal, R., "Privacy Risks, Emotion, and Consumer Willingness to Share Personal Health Information," *CHIDS Research Briefing* (4:1A) Center for Health Information and Decision Systems, Robert H. Smith School of Business, University of Maryland, Spring 2009, pp 1-4.

CHIDS Contact Information

Director – Ritu Agarwal, Professor and Robert H. Smith Dean's Chair of Information Systems

Center for Health Information and Decision Systems
Robert H. Smith School of Business, University of Maryland
College Park, Maryland 20742
Ph: 301.405.2216; chids@rhsmith.umd.edu
www.smith.umd.edu/chids

CHIDS Membership Information

Become a corporate member of CHIDS and realize the benefits of having access to a world-class team of researchers. Gain:

- ★ Access to top scholars
- ★ Customized research programs
- ★ Early insights from research
- ★ Priority access to research projects
- ★ Opportunity to influence CHIDS' research agenda
- ★ On-demand MBA student resources
- ★ Quarterly updates on key HIT activities
- ★ Participation in bi-annual conferences

CHIDS Corporate Members and Affiliates

Johnson & Johnson
CISCO Systems Inc.
Children's National Medical Center
Westat Research
Inspire
Ozmosis