

A COMPARATIVE STUDY OF CONCERNS FOR HEALTH INFORMATION PRIVACY ISSUES IN TAIWAN AND CHINA

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ABSTRACT

Medical information breaches incidents are on the rise and it is a major barrier to the adoption of health information exchange (HIE). The concern for health information privacy (CFHIP) has been known of its critical role in health information sharing. Yet it is still in need of more related studies to clarify how does it exercise in the process of HIE. This study aimed to provide an overview of HIE in Taiwan and China and develop a comprehensive literature review on CFHIP related issues.

KEYWORDS: Concerns for Health Information Privacy, EMR, EMR Exchange, Health Information Exchange, and Intention

INTRODUCTION

Thanks to the digitalization of medical records, people are more likely to have their personal health information (PHI) including demographic data, medical history, and laboratory test results stored in hospitals' databases. Likewise, tons of financial and demographic data are collected and stored in a digital format for health insurance reimbursement purposes. Electronic Medical records (EMR) are now a necessity in the healthcare system, having been adopted by the most of healthcare institutions. The adoption of HIE, for example, the EMR exchange throughout the health care industry has aimed to improve care quality and provide clinicians with more complete patient records and to support better clinical decision making. A whole scale of HIE adoption in healthcare industry seems to be able to improve coordination between care providers and assure patient safety. However, medical data breaches have been reported in recent years (O'Hara, 2017) and made people worry about their health information privacy (Donnelly, 2017). The health insurance giant company Anthem Inc. was shown on the news headlines for losing 37 million people's medical data, the data breaches have revealed the vulnerability of the whole healthcare system's security. Those lost data could be used to set up a new bank account or engage in a business transaction. In the HIPAA security rule, the Department of Health and Human Services noted that "the rise in the

adoption rate of these technologies [electronic health records] (HIPAA, 1996) increases the potential security risks.

Health service providers would be earlier reimbursed by uploading digital medical insurance data in the beginning of each month. With the driving force (health insurance reimbursement) from National Health Insurance Administration (NHIA), the Taiwan Hospitals have altogether established a solid health information infrastructure to integrate and share patients' data just in seconds. Besides, Taiwan's health insurance system is a single-payer healthcare system that all the medical institutions are paid by the NHIA. Most of the health insurance information will be uploaded to the NHIA centralized database. Taiwan's NHIA has been operating for nearly 23 years, which covers a national health insurance system. There is no other medical database in the world like this that covers data from the entire population in a single health insurance database system. In the past two decades, the Ministry of Health and Welfare (MOST) in Taiwan has bit by bit promoted the development of EMR exchange system and standardized procedures so we can avoid unnecessary treatments by checking our medical history. In 2012, Taiwan launched the National Health Insurance Research Database (NHIRD) derived from the system managed by the NHIA and maintained by the National Health Research Institutes. The NHIRD provided de-identified data to scientists in Taiwan for research purposes. With mass controversy over the purpose of collecting people's medical data is not for academic interests, people gave in their sensitive medical data (like nude picture before surgery) without consciousness. Due to the lawsuits between Taiwan Association for Human Rights and the NHIA, the application of NHIRD was terminated on the 28th of June, 2016.

People are concerned about the privacy of their personal medical data and its security as it is stored and transferred across the healthcare system (Ancker et al., 2015). These concerns would have influences on how people value EMR exchange usage in healthcare industry. In particular, Agaku et al. (2014) found that patients deliberately withheld their health information from their care providers due to the concerns over the security of EMR systems. These two studies present a problem needed to be solve immediately, which is how patient concerns could affect people's behavior to share personal information or withhold it instead.

The application of EMR exchange is a double-edged sword, people would like to rely on its ability to improve our medical quality, but on the other side they want to keep it privately and are unwilling to use EMR exchange. People's responses pointed out the ethical issues in concerns of health information privacy in modern healthcare industry. Researchers (Li, 2010; Smith et al., 1996) tried to define privacy, information privacy and concerns for information privacy in e-commerce environment. However, there is still a gap in our knowledge about how to manipulate people's concerns for health information privacy (CFHIP) in the healthcare setting. To address the health information privacy issues in healthcare industry, this study attempted to highlight the unique nature of healthcare industry and enumerate related studies in IS field for a comprehensive concept on this issue. The aims of the present work are as follow: 1) To review the HIE current states in Taiwan; 2) To develop a research model and examine the model in Taiwan; 3) To conduct a comparative study in China.

LITERATURE REVIEW

Health information exchange in Taiwan

In Taiwan, an integrated personal EMR exchange platform was launched in 2011, which is so-called “EMR Exchange Center (EEC)”. Under patient’s consents, physicians can retrieve patients’ medical records that stored in other hospitals by using EEC. There have been 402 medical institutions participating in EEC project until 2017(EEC · 2017). Physicians can look up their patients’ medical histories from outpatient department (OPD) and inpatient department (IPD), medical Image and reports, lab test data, medication history on EEC when they in clinic visits. Moreover, in 2014 NHIA (National Health Insurance Administration) deployed two more programs to empower Taiwanese to have their own health data; they are “Pharma Cloud” and “My Health Bank”. NHIA’s Pharma Cloud contains personal medication history (update data everyday) and the physicians who are authorized by patients would review patients’ medication and medical history. “My Health Bank” shows the history from OPD and IPD, allergic information, intention to organ donation and hospice care, medical history form for use in dental practice and vaccination. According to the report (NHIA, 2014), the reasons of low usage rate of Parma Cloud system might be: 1) lack of intention of physician; 2) lack of intention of patients. Previous studies (Angst, 2009; Bansal et al., 2010; 2015) emphasizes the impacts of information privacy issues on the individual’s intentions to disclosure their health information are all supported. Patients’ awareness is the most important factor to promote their health status. Patients should play the major role in the clinic visit and ask physician to check their medical history (active participation).

Personal Health Information and Concerns for Health Information Privacy

The US privacy regulations of the Health Insurance Portability and Accountability Act of 1996 (HIPAA) was issued in 1996. The regulations require health care providers to provide patients with a privacy notice that informs them who will have access to their records without their explicit consent and about patients' rights to inspect and amend their own records. In this medical information protected law, "personal identifiable health information" is defined as health information, including demographic information that identifies the individual, and pertains to an individual’s past, present, or future physical or mental health, diagnosis and/or treatment or payment for health care. PHI(HIPAA, 1996) includes the 18 identifiers :1)Name; 2)Address; 3)Dates related to an individual; 4) Telephone numbers; 5) Fax number; 6) Email address; 7)Social Security Number; 8) Medical record number; 9)Health plan beneficiary number; 10)Account number; 11)Certificate/licence number; 12)Vehicle serial numbers; 13) Device serial numbers; 14)Web URLs; 15)Internet Protocol (IP) Address; 16) Finger or voice print; 17)Photographic image and 18) Any other characteristic that could uniquely identify the individual. These identifiers could be used to identify the individual or the individual’s relatives, employers or household members.

Health information with a high degree of privacy, it they were being leaked, may cause people distrust medical institutions and health insurance provider and lead to the consequence of people’s warying about information disclosure. In addition to facilitating access to information, saving costs and improving the quality of health care, digital health information poses new threats to

the privacy of patients (Mercuri, 2004). Therefore, the study of health information privacy concerns is in need of more researches to protect our health information and prevent further potential damages.

Li (2010) conducted a content analysis on information privacy issue and proposed an integrated framework for concern for information privacy (CFIP) in the e-Business Context. Two empirical studies were published by Li et al. (2014) to validate partial constructs proposed in his 2010's work. Bansal et al.'s study (2015) pointed out the importance of research context in theory development. To our aim to propose the integrated framework of health information privacy concern, we adapted Li's work (2010) and thrived to elaborate more constructs to fit in healthcare context.

MODEL DEVELOPEMENT

The result of the literature review yielded the initial research framework in this study, which included six dimensions and three mediator variables, they are: 1) Concerns for health information privacy; 2) Intention to provide personal health information; 3) Personal dimension (demographics, computer anxiety, health status and disease severity); 4) Environmental dimension (cultural and government regulation); 5) Organizational dimension (hospital reputation, physician reputation, physician-patient information asymmetry, and perceived hospital information security); 6) Information contingency (type of information and information sensitivity). The three mediator variables are: trust, perceived risk and perceived benefit. The researchers complied the operational definition of each construct based on the references and the characteristics and uniqueness of the healthcare industry, and then invited the experts to validate the research framework and operational definitions.

There was a three-round expert review held in this study. The expert committee had two professors in the field of medical informatics, three information management professors, one professor in computer science and one medical center administrator. The first expert meeting held on the 27th of June, 2015 mainly focused on the evaluation of our research framework and the questionnaire draft. After the first expert review, the study framework was modified. The "information type", "culture" and "intention" constructs in the initial research framework were modified or deleted. The third expert meeting was held to ensure the items could be used in Taiwan and China.

As Bansal et al. (2010) pointed out that information sensitivity is usually derived from the type of information, personal characteristics and health status will affect the sensitivity of information, that is, people perceive different degree of sensitivity toward the same information based on their different personal characteristics and health status. Malhotra et al. (2004) applies the "type of information", which defines information as sensitive or insensitive by binary category. However, from the statistical point of view, it is highly likely to show collinearity if we combined "type of information" and "information sensitivity" in this study. In the discussion of "culture" construct, a total of 20 items derived from the culture related literatures and the experts suggested that the questionnaire would be too many items to deter the respondents from willing the answer complete questionnaire. In the end of expert review, we turned "culture" to a nominal variable to stand for the nationality. In the "Intention to provide healthy information" construct, we defined it as "patients' intention to provide their own health information to doctors when they

are in a clinical visit". In a similar study (Bansal et al., 2010), the research context they used was a health website. The "intention" in that study is "the willingness to provide information on the health website". In the study of Hwang (2012) uses the "willingness to provide health information to doctors", but this hypothesis was not supported in that study. After the expert review, they suggested that the behavior of "seeking medical care" is quite different from "online search for health information". It is neither voluntary, nor unnecessary behavior (except for the aesthetic medicine or advanced health check service). Most people visit doctors only when they don't feel well and want to relieve their discomfort immediately. To get proper treatments, the questions asked by the doctors are usually answered as detailed as they can, hoping to recover earlier. Therefore, it seemed that we ought to find a more solid definition for intention in this study.

Most people will provide the necessary information to their doctor. Electronic medical records exchange has been promoted for many years in Taiwan, the optimal goal of government is to reduce the medical error and to improve medical quality. By using EEC, people are empowered to control the access to their own medical history. This is the foundation of patient awareness of taking responsibility for their health. The low usage of EEC is due to the lack of motivation from both sides of patient and physician. When it comes to a clinical visit, the doctor normally asks the past six months of treatment or medication situation, most people be in non-medical related areas should not be able to completely memorize the detailed medical history. But they can actively to ask the doctor to access their own past medical records. Or when the doctor wants to access his past medical record, he is willing to sign consent to access the electronic medical record. The intention of this behavior is more practical in the context of this study. Along with the Health Belief Model (HBM), the use of its own concept of health promotion is similar in this study, in which the health promotion behavior is the disclosure of complete health information in this study that makes medical diagnosis and related treatments more proper and solid. Based on the results of expert meetings, the intention construct was modified to "the intention to use EMR exchange ". Figure 1 shows the modified research framework after expert meeting.

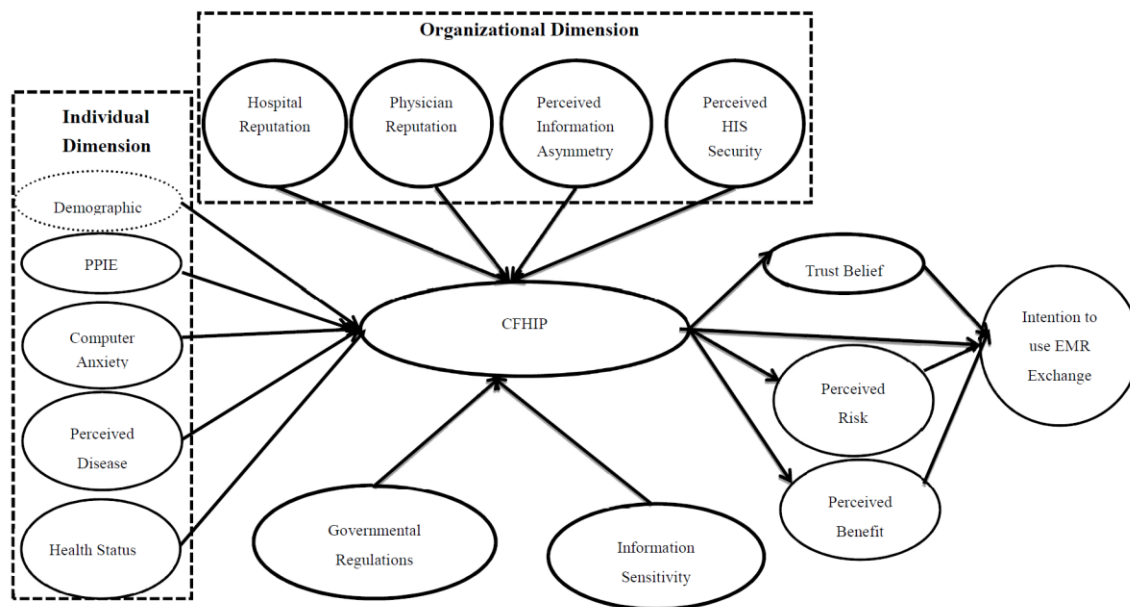


Figure 1 Modified Research Framework

DISCUSSION AND CONCLUSIONS

A comprehensive literature review was conducted and the content analysis was also used to analyze these collected articles. An initial research framework and related constructs were proposed based on the result of literature review and content analysis. Then the expert meetings were used to validate the initial research framework. This integrated research framework includes: Individual dimension (Demographic, Previous Privacy-Invasion Experience, Computer Anxiety, Perceived Disease and Health Status), Organizational dimension (Hospital Regulation, Physician Reputation, Perceived Information Asymmetry and Perceived HIS Security), Governmental Regulations, Information Sensitivity, Trust belief, Perceived risk, Perceived Benefit, Concern for Health Information Privacy dimension, Intention to Provide Health Information dimension. This study is going to carry out the validation of our research framework in Taiwan and China. The results of the presented work would have contributions on the health privacy issues to the healthcare industry in Taiwan and China.

ACKNOWLEDGMENTS

The authors thank the reviewers for their valued comments and constructive suggestions that improved this work.

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