



Special Communication

Greater patient health information control to improve the sustainability of health information exchanges

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ABSTRACT

Health information exchanges (HIEs) are multisided platforms that facilitate the sharing of patient health information (PHI) between providers and payers across organizations within a region, community or hospital system. The benefits of HIEs to payers and providers include lower cost, faster services, and better health outcome. However, most HIEs have configured the patient healthcare consent process to give all providers who sign up with the exchange access to PHI for all consenting patients, leaving no control to patients in customized what information to share and with who. This research investigates the impact of granting greater control to patients in sharing their personal health information on consent rates and making them active participants in the HIEs system. This research utilizes a randomized experimental survey design study. The study uses responses from 388 participants and structural equation modeling (SEM) to test the conceptual model. The main findings of this research include that patients consent rate increases significantly when greater control in sharing PHI is offered to the patient. In addition, greater control reduces the negative impact of privacy concern on the intention to consent. Similarly, trust in healthcare professionals leads to higher consent when greater control is offered to the patient. Thus, greater control empowers the role of trust in engaging patients and sustaining HIEs. The paper makes a theoretical contribution to research by extending the unified theory of acceptance and use of technology (UTAUT) model. The findings impact practice by providing insights that will help sustain HIEs.

1. Introduction

Health information exchanges (HIEs) are multisided platforms that facilitate the sharing of patient health information (PHI) between many participating sides: patients and various types of providers, such as hospitals, primary care physicians, and lab test providers [1]. Typically, providers import patient medical records to exchanges or their edge servers for other physicians to access when needed. Patients often see a variety of physicians for the different ailments at different points in time over their lifespan, and this makes their medical records highly fragmented. HIEs allow for integration of a patient's record from multiple sources across the time horizon. This makes the entire patient history available to any physician treating the patient prior to the delivery of care. The benefits stemming from such a practice are the avoidance of duplicate tests, when possible, and the availability of the record itself. This potentially could lead to greater practice efficiency and lower costs for payers (i.e., insurance companies) who now do not have to pay for duplication. Providers also benefit by having the entire patient information available for making decisions about patients. This helps providers make quality decisions about the patients' conditions

which as a result, reduces medical errors and improves health outcomes. While the financial benefits of provider practices are not well established, federal incentives and penalties stemming from meaningful use initiatives provided the motivation for greater participation. Availability of patient records to providers also ensures that patients do not receive prescriptions that interact with other prescription drugs they are taking. This leads to better patient safety.

As HIEs are structured, the parties that benefit the most are the payers (i.e., insurance companies) and, to an extent, physicians, regarding cost and practice efficiencies. Patients do benefit not necessarily by lower cost, as such savings are often not passed on to patients, but by the availability of their medical history to the attending provider. For example, when a patient shares his or her PHI with providers and as a result, unnecessary tests are avoided, the insurance company saves the cost of the eliminated redundant tests. However, the insurance premium for that patient does not decrease because of savings that the insurance company incurred when the patient shares his or her PHI. HIEs benefit payers and indirectly providers, on occasion. HIEs cannot share patients' PHI with physicians who are part of the health exchange without getting consent from the patients [2].

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The survival of exchanges is therefore linked to provider adoption of HIE (become a participating member of the HIE network). Physician adoption is better if a greater number of patients consent to sharing information; however, consent rate is still not up to the expectations [3]. Research on improving the adoption of HIEs is currently focused on the adoption of providers [4]. Further, most patients are passive participants of exchanges even when they opt to share, as they are only informed of their benefits that stem from consenting to share their PHI.

However, if patients become active participants in HIEs, this ownership and participation relationship could change the dynamics regarding sustainability of HIEs. Further, it could also open up avenues for revenue generation and a wide variety of specialized services that HIEs can offer in the future. This is especially true as HIEs of the future will likely contain the medical records of other family members, and these can be harnessed for better preventive care, among other things. For example, in the future, patients may be able to choose to share their health information among family members. This could help healthcare providers make even better decisions when the entire family history is available. A mechanism for HIEs to engage patients is to offer more control to the patients who want to share their personal health information.

The privacy rule of the Health Insurance Portability and Accountability Act (HIPAA) grants covered healthcare providers as HIEs the right to tailor patients' consent forms, material, procedures, and options as appropriate¹. In addition, state privacy laws vary. It is this provision—that is, the broad level at which the regulations of the HIPAA have been defined with regard to data in HIEs—that has led to implementations by HIEs that violate the principle of least privilege. Most healthcare providers do not grant patients any level of granularity in controlling which information they share or with whom. This paper studies the impact of providing patients greater control in managing the sharing of their medical records on consent. This paper attempts to answer two main research questions: Will greater control in PHI sharing yield higher HIEs consent? How does greater control in PHI sharing change the relationship between independent variables (e.g., privacy concerns and health concerns) and intention to consent? Using a randomized experimental survey design, this paper tries to answer these questions. This research contributes to theory by extending the unified theory of acceptance and use of technology (UTAUT) model in the context of sharing health information electronically. This paper also provides practical insights on how to sustain HIEs and increase consent rate by offering greater control in PHI sharing to patients.

2. Background

2.1. Literature review

Most of the current research is focused on investigating the barriers of adoptions for healthcare providers, and finding ways to ease the process and enhance the experiences [5]. Although the patient is the central beneficiary of the technology in terms of improved health outcomes and reduced medical errors, limited literature has investigated the patients' side of the equation [4]. This section highlights some of the literature in the information sharing in health information systems. In general, HIEs are positively considered. However, this attitude does not translate into sharing intention or behavior. Yaraghi, Sharman [6] suggest that older and female patients have a higher tendency to sharing their PHI via HIEs. Caine and Hanania [7] findings suggest that patients do not want all of their medical information shared with all possible recipients. Although in these authors' study the type of information that can be shared and the type of recipient that can access the information varied by patients, all patients agreed to partial access.

On the contrary, Adams, Budden [8] reported that the majority of

respondents would not restrict access to their shared information. Also, Hassol, Walker [9] found that most patients had a positive attitude toward the user of their information in the electronic health record (EHR) and were mostly not concerned with the privacy of their information. Likewise, Ancker, Edwards [10] indicated positive consumers' attitude towards the use of HIEs and suggested addressing security concerns. Simon, Evans [11] investigated the barriers to consent with 62 patients in a focus group. The study reports three main concerns: security concerns, lack of knowledge of possible benefit to an individual's health, and the need for more information about the consent process. Grande, Mitra [12] found that the sensitivity of the information is not a barrier for sharing. Patients focus more on how the information will be used, rather than what information is used.

Tripathi, Delano [2] highlighted the significance of reaching out to patients on the willingness of personal health information through lessons learned from The Massachusetts eHealth Collaborative (MAeHC). Angst and Agarwal [13], on the basis of a survey with 366 participants, argued that patients can be persuaded to have their information digitalized and used in the EHR. Dhopeswarkar, Kern [14] stated that patients trust physicians, but do not trust employees when it comes to having access to health information. A survey of 170 residents in New York State shows that most people want to know who viewed their information [15]. Platt and Kardia [15] suggested that perceived benefits and quality of care are positively associated with more engagement in the system.

Dimitropoulos, Patel [16] argued that most patients agree on the benefits of sharing their health information, but they want to tailor the information that is shared. Weitzman, Kelemen [17] argued that patients do not want to share information about sexually transmitted diseases with providers. Yasnoff, Sweeney [18] emphasized the need to investigate ways to overcome barriers to health information sharing and increase sharing.

Demirezen, Kumar [19] suggested that HIEs have to offer value-added services to attract more healthcare providers and sustain the systems. Yaraghi, Du [20] explored drivers of the adoption of HIEs by healthcare providers and found that HIEs have large market share, and a high number of shared patients are more likely to adopt these systems than others. Despite the vast extant of studies relating to HIEs and concerns about security, prior research did not address the issue of HIEs by providing a personal health record (PHR) system to patients. This research is important as PHRs offered to patients by HIEs could improve patient involvement and engagement with HIEs, thereby improving their sustainability.

2.2. Conceptual model development

This work adapts the UTAUT model [21] to the context of HIEs. This study investigates how privacy concerns, trust in healthcare professionals, perceived usefulness, health concerns, and social influence affect the intention to consent. It also explores how offering patients greater control in sharing their PHI impacts this relationship, as Fig. 1 shows. This paper integrates trust and privacy concerns in the UTAUT model because they have been identified as main factors affecting the use of health information technologies [22,23]. Health concern is used as a facilitating condition in the healthcare context. In addition, this research tests how the UTAUT model changes if the sharing setting in HIEs changes. The following Sections 2.2.1-2.2.6 present arguments for all hypotheses in this study.

2.2.1. Patient control over PHI sharing

The literature cites many examples of the impact of greater control on the intention to disclose private information. For instance, in 2009, Facebook added a policy that allows its users to choose the recipients of each wall post, and Cavusoglu, Phan [24] investigated the causal effect of granting Facebook users more control over which information they can share and with whom. Their findings indicate that the new policy

¹ 45C.F.R. § 164.506(b).

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