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Adoption of Digital Allergy Card: A Mixed-Methods Approach

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Abstract

Due to the recent growth in the number of Personal Health Records (PHR) as well as the necessity for the development of digital solutions for reliable and accurate documentation of drug allergies, there is a need to explore digital solution as a Digital Allergy Card (DAC). Despite the advantage of using DAC, there are obstacles to taking this solution. While several studies raised privacy concerns as the key barrier to DAC adoption, there is no clear understanding of the variability of these concerns in relation to other factors which may overcome them. Therefore, drawing on situational privacy calculus theory, we propose a mixed-methods approach to assess the trade-off between perceived benefits and privacy concerns in different situations regarding DAC use. This study will provide insights to both academics and practitioners on PHR adoption by the identification of contextual determinants which can influence the adoption of a DAC.

Keywords personal health records, adoption, privacy calculus, mixed-methods, digital allergy card

1 Introduction

Previous studies on the Personal Health Records (PHRs) adoption identified several determinants that negatively or positively impact patients' behaviour (e.g., Laugesen and Hassanein 2017; Li et al. 2014; Whetstone and Goldsmith 2009). Most previous studies of PHR adoption applied technology acceptance model or unified theory for the acceptance and use of technology and assessed influencing factors such as attitude, usefulness, and ease of use (e.g., Noblin et al. 2013; Razmak and Bélanger 2018; Wu 2016). Moreover, the existence and survival of a PHR are largely driven by making patients' PHR's available for access by physicians and other stakeholders. This access is limited by regulations and by individuals' privacy concerns. Several researchers argue that privacy issues are a real barrier to PHR adoption (e.g., Roehrs et al. 2017) (e.g., Roehrs, Da Costa, da Rosa Righi, & De Oliveira, 2017). In addition, several studies and reports show that most people have serious anxiety about how their health information is obtained and used (Angst and Agarwal 2009; Zhang et al. 2018). Privacy concerns arise when individuals are asked to provide health information to obtain the full benefits of using a PHR (Li et al. 2014). These concerns may even hinder the adoption of PHR (Li et al. 2014). Therefore, exploring the drivers of PHR adoption considering privacy concerns is salient.

However, while many studies have highlighted privacy concerns as the main barrier to PHR adoption, the variability of those concerns in relation to other factors such as the benefits or the context may override them (Li et al. 2014). The "calculus behaviour" is omnipresent in the adoption of technologies. Individuals may accept some difficulties if they see a clear benefit from using technology (Gagnon et al. 2016). Based on privacy calculus, individuals will volunteer to adopt an online service if the risks are outweighed by the benefits. Similarly, for PHR, people would need to agree to build their medical profiles online and share them with healthcare providers to receive necessary medical care if people believe that this trade-off is beneficial to them. General privacy concerns may be overridden by situational factors, which serve as critical indicators of whether a technology use situation is more or less risky, or more or less beneficial (Malhotra et al. 2004). All the medical care needs are not equivalent. For example, some authors found that PHRs are particularly valuable for emergency situations (e.g., Morales Tirado et al. 2020). Thus, contextual elements are important in privacy calculus because they can mitigate or accentuate the impact of risks and benefits on the intention to use. Therefore, we propose the following research question:

How does the situational trade-off of benefits and risks affect the adoption of a PHR?

To respond to this research question, this study aims to leverage elements of situational privacy calculus theory, to develop and test a model for assessing the situational trade-off affecting patients' PHR adoption.

2 Background on Personal Health Records Adoption

PHR is defined as a record of an individual's health information whose access is controlled by this individual (Roehrs et al. 2017). This information can be collected automatically with wearables, captured from other information technology (IT) applications, or entered by doctors or individuals (Jiang and Cameron 2020). PHRs can integrate a variety of health information including information about the daily routines of individuals or clinical information, informing on physicians' reports about the health status of the individual (Roehrs et al. 2017). This information is important for the safety of individuals (Sherer 2014). It is insightful for therapeutic decision-making, guiding individuals in the self-monitoring of their health, or helping individuals to change their lifestyle. Indeed, the adoption and use of a PHR by an individual include the authorisation to disclose his or her health information in order to obtain all the benefits related to this PHR.

Among all types of PHR, drug allergy information is clinical information that allows the physician to choose the right treatment to administer or to prescribe the right drug for the patient to avoid adverse reactions (Pawankar et al. 2013). These adverse reactions can be moderate with skin rashes or more severe with respiratory problems, anaphylactic shock, or death (Roehrs et al. 2017). The existing problems in the drug allergy information process regarding accessibility, completeness, and reliability have led several allergist researchers and practitioners to propose the alternative of the mobile application to trace allergy information and make them available at any time and place (Brockow et al. 2016; Ithnin et al. 2017; Khalil et al. 2011).

Since the previous drug allergy information process was not optimal to transmit the right information at the right time, the European Academy of Allergology and Clinical Immunology proposed the implementation of allergy applications. The digital allergy card (DAC) aims to ensure patient safety by making allergy information available for optimal therapeutic decisions (Ngassam et al. 2022). Patients

express their satisfaction with DAC that it gives them the opportunity to record more information than on paper and the information is better stored in a database. In addition, patients' allergy information is more accessible through DAC, which allows physicians to use it for making therapeutic decisions. DAC also helps in proofing information, as it makes it possible to know whether a reported allergy by a patient is actually confirmed by a physician. DAC also facilitates the communication between patients and physicians (Ngassam et al. 2022).

2.1 Situational Privacy Calculus

The adoption of online services follows a "calculus behavior" which is the representation of the internal trade-off of consequences (risks and benefits) while using online services (Li et al. 2010). Regarding the risks of using online services that represent the negative part of the calculus behaviour, privacy concerns represent the most popular risk (Roehrs et al. 2017). Therefore, the privacy calculus has been used in many studies to explain the adoption of online services such as e-commerce, social networks, and mobile and web apps (Li et al. 2010). Three concepts have been highlighted in the literature to measure privacy including perceived privacy risk, privacy control, and privacy concerns (Jozani et al. 2020). Unlike the other two concepts, privacy concerns are not absolute concepts; rather, they are people's perceptions about their rights and control over their personal information. Previous research had used privacy concerns to reflect the risk/cost dimension of the privacy calculus equation (Sheng et al. 2008).

In this work, we use the privacy calculus perspective as the trade-off of the consequences of information disclosure in a PHR, considering privacy concerns as the main risk. These concerns, however, can be overcome by the benefits that the individual can gain from using the online service (Jozani et al. 2020; Scarpi et al. 2022). An e-health application as an online service requires or asks the individual to disclose his/her health information to obtain the full benefits that will have a positive impact on his/her health condition (Li et al. 2014) in terms of health information, emotional support and safety (Buntin et al. 2011).

Moreover, the trade-off conducted by individuals is linked to a given situation (Li et al. 2010). Several studies show the importance of the context in the decision to use a service. For example, an application for the weather will seem more useful to an individual living in an area where there are very often strong storms and at a time of year when these storms are frequent (Sheng et al. 2008). Similarly, there are situations where the individual may see the importance of a PHR and decide to adopt it despite the privacy risks (Li et al. 2014). The context or situation dependency has been demonstrated in several areas such as marketing, e-commerce, and online weather services (Omary et al. 2011). It has been shown that people's needs very often vary depending on the situation they are in. If the need is strong, the individual will tend to disregard the risks to use the service that is proposed. Apart from the emergency (versus non-emergency) contexts that are mentioned in the literature as levers for the adoption of mobile applications (Thomas et al. 2003), there is lack of studies highlighting the importance of contexts to mitigate or accentuate the impact of risks and benefits in the adoption of PHR. Therefore, by applying situational privacy calculus theory, we explore the contextual drivers of trade-offs for PHRs adoption.

3 Research Method

A mixed-methods design contains elements of both qualitative and quantitative methods (Tashakkori et al. 1998), which is suitable when an exploration of a phenomenon is required to further understand it for the purpose of explanation beyond what a single method could provide (Venkatesh et al. 2013). In this study, we follow a developmental mixed-methods, since we first conducted a qualitative study and used the findings from this phase, in concert with situational privacy calculus literature, to develop a research model. We will test the proposed hypotheses in the second phase of this study, using a scenario-based factorial design survey. The factorial design survey allows to explore the informational elements used by the subjects to respond to the survey questions. This design helps to understand how different people respond differently to the same information (e.g., visual or text) cues (Wallander 2009).

3.1 Phase 1: Qualitative Study Design

For the qualitative phase, we utilized an interpretive phenomenological approach (Creswell and Creswell 2017) to leverage interview data from patients and physicians, helping us to contextualise the deriving elements (levers and barriers) of privacy calculus in a PHR adoption (DAC in this study).To reach a target relevant to the context of this health-related research, we worked with a French hospital for interviews with different profiles. We focused on the key actors in using a potential allergy card. We targeted patients and doctors to gather all valuable data related to these actors' use of this allergy card.

We contacted several patients and doctors; our final sample comprised 11 patients and 5 doctors. We drew up an interview guide to conduct semi-structured interviews with this sample in France. We asked them holistically about their experience with allergies and mobile health apps, their representation of a DAC, as well as their justified intention to use a DAC. These interviews last around 30 minutes each and were all recorded and transcribed. Based on the transcribed interviews, relevant themes were inferred by the two authors separately and from different transcribed interviews (one for patients and the other for

doctors) using an inductive thematic analysis, which is inspired by the grounded theory (Corbin and Strauss 1990).

Participant	General code	Supportive quotes
Patient#1	Physician's recommendation	"I might not have had the reflex to do that. If it came from the doctor, yes"
Patient#9	Previous experience with severe allergic reaction	"I think that for me, since I have had a very serious allergic reaction, I think that this application is very useful"
Patient#11		"I've struggled so much with allergies and such that yes."
Patient#2		"… then suddenly he had a fever. We gave him paracetamol and 20 minutes later he had a skin reaction, and that's what had been confirmed, and he did allergy tests, he is allergic to dust mites, and we have a carpet (…) We expect him to have one [digital allergy card]."
Patient#3		"I remember that one day the doctor told me oh no your husband is having a heart attack when no it was not a heart attack, It was really his allergy. You see, that's why I think these [digital allergy cards] are things that can be useful."
Patient#8	Context of mobility	"A digital card, I know that since I always have my phone with me, I could take it everywhere with me since I like to travel"
Patient#3		"… a digital card I know that since I always have my phone with me I could take it everywhere with me since I like to travel and then for the card for the paper card (…) I'd be I'd feel safer to have it on me."
Patient#9		"And digital technology goes everywhere, it's fast. Right now, I'm walking around with a medical file like that, a big file."
Patient#5		"I have a problem, I have my local doctor, okay, my family doctor and I have my pneumologist who follows me regularly because I have a problem with my heart… I don't go on vacation anymore because of this"

Table 1. Examples of Extracted Codes and Supportive Quotes

All interviews were assessed by a first code, close to the respondents' words. Then, a more general coding was performed. The results' coding scheme was discussed with the other members of the team. Disagreements were discussed until consensus was achieved (Zwaanswijk et al. 2011). Several relevant elements related to individuals' adoption of the DAC emerged (see Table 1). Based on these results, we chose to integrate the last two aspects including '*the level of severity of previous drug allergies*' (severe versus mild) and '*the mobility context*'[1] (sedentary versus travelling) as moderators of our model that can likely influence the level, direction, and presence of the trade-off relationships in the proposed privacy calculus model. The choice of these variables in our study lies in the fact that they are adapted to a two-factor experimental study since the different occurrences of these variables are mutually exclusive. In addition, these variables are also relevant to the PHR adoption topic in the sense that

[1] A digital allergy card serves as a portable and easily accessible tool to communicate essential information about one's allergies. Having a digital version can be more convenient and reliable than carrying a physical card, as it can be updated easily and is less likely to be misplaced.

several studies have highlight the interest of IT application for health information ubiquity for the continuity of care (Gordon et al. 2012) and a threat severity have been assessed elsewhere as a strong predictor of protective behaviour (Norman et al. 2015; Rogers 1975). Thus, a previous severe allergy may positively stimulate an individual intention to adopt a preventive or protective solution against a next potentially severe reaction.

3.2 Research Model and Hypotheses Development

The results of interviews suggest the level of severity of previous drug allergies and the mobility context are indeed key supportive moderators to the trade-off between patients' privacy concerns and perceived benefits towards a DAC adoption, as shown in Figure 1. Based on the findings from interviews, the participants' perceptions about benefits/privacy concerns towards DAC adoption can be changed depending on the levels of mobility and severity. In a way that the strength or even the direction of privacy concerns-benefits-adoption could vary across different levels of these two variables. Since the primary interest of this study is in understanding how the effects of privacy concerns/benefits variables on DAC adoption are contingent upon the existence of mobility and severity levels, we propose to test the moderation role of these two variables. The mobility context coupled with the severity represent the elements of context that we manipulate in this study. This corresponds to the definition of context that involves at least one entity (place, person or object). We also include control variables of age, gender, information sensitivity, experience with e-health applications, frequency of past reactions and realism of the scenario. Information sensitivity refers to an individual's attitude toward revealing different information while interacting with a specific application (Jozani et al. 2020).

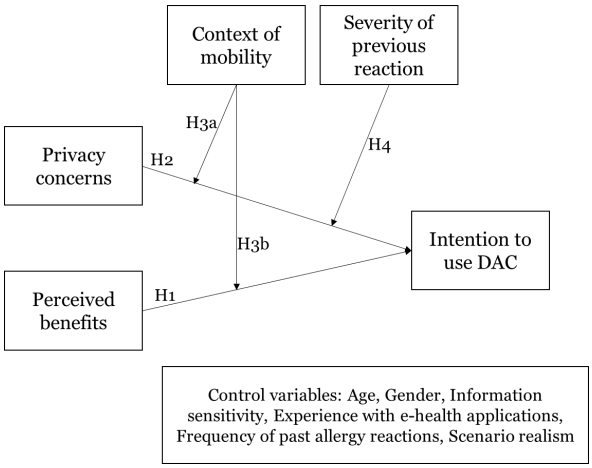

Figure 1: Proposed research model

In terms of benefits, a PHR can have benefits in terms of information, such as improving the storage, structuring and completeness of information, facilitating accessibility and even ensuring the reliability and traceability of information. Then we have benefits that can be emotional when there are interactions allowing individuals to find comfort in relation to their situation (Zhang et al. 2018). This benefit is more visible in the context of forums or online experience sharing networks. We can also have benefits related to health and protection of the individual for the prevention or treatment of a disease (Vance et al. 2015). The perceived benefits variable is used to define the usefulness of PHRs. It combines information and health benefits. Individuals must disclose their health information so that physicians can access them to make the best therapeutic decision (Norman et al. 2015; Rogers 1975). In other cases, the disclosure of health information allows the application to give precise guidelines for the individual to better self-manage his/her health. Previous studies argue the impact of users' perceived benefits on the intention to use an application (e.g., Whetstone and Goldsmith 2009).

Despite all the associated benefits, health information disclosure raises privacy concerns. Health information is very sensitive and individuals have several reasons for not disclosing their information such as misuse or stigma (Zhang et al. 2018). Privacy concerns refer to the inherent concern of an individual regarding the potential loss of private information (Zhang et al. 2018). It results from a privacy risk-benefit trade-off that the individual performs before deciding on adopting a recommended behaviour (Li et al. 2010). This trade-off defines the fact that individuals are more willing to disclose their information when the benefits encompass the risks of disclosure. Several studies have shown that privacy concerns negatively influence the intention to use (e.g., Hassandoust et al. 2021; Hsieh et al. 2017). Meaning that if individuals have more privacy concerns, the less they are willing to use the

technology since it implies the disclosure of their information. However, previous studies have shown that privacy concerns are mitigated depending on the context because a user's concerns and needs vary with the context in which he/she uses an application (Sheng et al. 2008). Contexts are situations and environments about existing or occurring entities. An entity can be a person, place, or physical or computational object (Hwang 2005). Drawing on privacy calculus theory, the direct impacts of benefits and privacy concerns on intention to use a DAC can be measured, however these impacts can be mitigated or accentuated depending on the context or situation of use. Therefore, we hypothesise:

H1: Perceived benefits has a positive effect on the intention to use a DAC.

H2: Privacy concerns has a negative effect on the intention to use a DAC.

Several constructs can influence the user's decision to adopt new technologies for health. Previous studies have highlighted the moderating role of several variables. For example, the moderator role of age, gender, and trust in mobile health service adoption and the moderator role of national culture on adoption intention of wearable healthcare devices (e.g., Zhang et al. 2022; Zhao et al. 2018). In this study, our findings have shown that the level of the allergy's severity and the mobility context are essential supportive moderators of the link between patients' privacy concerns and perceived benefits. For example, Patient#9 declared the application was very useful because he had severe allergies. This situation demonstrated that the allergy's severity could influence his intention to use the new application. Patient#5 also claimed he couldn't go on vacations anymore because he has his local doctor near where he lives (see quotes in Table 1). This case showed that the mobility context might impact the perceived benefits of the application. We will manipulate and test these two moderators during the two-factor experimental study to see the modification of benefit and risk perceptions according to the assigned values. Each of these variables is measured by two mutually exclusive values, which is appropriate for the two-factor model. Regarding the *individual context of mobility*, one of the major interests of e-health applications is the accessibility of information outside the institutional barriers of the hospital. This is particularly important for the continuity of care when the individual goes to another hospital or when traveling. E-health applications benefit patients, especially in medical tourism, by improving access to healthcare services, enhancing patients' experience, saving costs, and having more effective outcomes (e.g., timely treatment for reactions) (Bokolo 2021), while travelling. We, therefore, explore two situations between individuals who are traveling and individuals who are sedentary. In the context of e-health applications these categories are mutually exclusive because, in the case of sedentary individuals, the need for the e-health application to facilitate the ubiquity of health information is less important than in the other case where individuals must consult different doctors in different hospitals. Thus, we hypotheses:

H3a: Sedentary lifestyle accentuates the impact of privacy concerns on the intention to use a DAC more than a travelling lifestyle.

H3b: Sedentary lifestyle mitigates the impact of perceived benefits on the intention to use a DAC more than a travelling lifestyle.

In addition, based on the results, we add a stimulus related to the severity of the previous allergic reaction. Severity of the previous reaction refers to the intensity of the adverse drug reaction (Edwards and Aronson 2000) a patient experienced before. Adverse drug event is a harm caused by medical intervention of using a drug. These events might be preventable or non-preventable. Adverse drug reaction is a nonpreventable adverse drug event happening with usual medication use (Lee et al. 2022). These drug reactions are not associated with medication errors. Side effect is a common term typically used to describe these reactions. Assessment of the severity of drug reaction is crucial to aid prevention or reduce patient burden (Ithnin et al. 2017). The severity of drug reactions can be classified as grade I, cutaneous symptoms; grade II, mild systemic reactions; grade III, life-threatening systemic reactions; grade IV, cardiac or respiratory arrest (Ring and Messmer 1977). In this study, we defined grades III and IV as severe reactions. The severity of the previous allergic reaction may trigger the patient's desire to engage in protective behaviours to prevent further reactions or mitigate the effect of reactions that may occur. Researchers argue that a bad allergy experience influence the patients' decision in using DAC, which helps them to better manage their future allergic reactions (Ngassam et al. 2022). We therefore hypothesize that this variable may mitigate the individual's perception of the risks associated with the use of the application. We distinguish between the level severe and mild. Therefore, we posit the following hypothesis:

H4: A previous severe reaction mitigates the impact of privacy concerns on intention to use more than a previous experience with a moderate allergy reaction.

3.3 Phase 2: Factorial Design Survey

In the second phase of our mixed-methods design, we will empirically test the proposed relationships that is developed based on the literature and the input from the first phase of this study. We propose to use an experimental design with the scenario-based method, which allows us to manipulate variables and test causal relationships. In this study, we employed a 2 (severe versus mild) X 2 (sedentary versus traveller) factorial design (as shown Figure 2). Factorial design survey approach uses vignettes and allows for the manipulation of many factors within those vignettes (Johnston et al. 2016). Vignettes are instrumental in capturing responses to concerns that may typically be subject to social desirability and acquiescence biases. Respondents provide more accurate and honest responses when answering from the perspective of actors presented in hypothetical vignettes instead of from their own personal perspectives.

	Traveller	**Sedentary**
Severe reaction	Scenario 1 = severe + traveller	Scenario 2 = severe + sedentary
Mild reaction	Scenario 3 = mild + traveller	Scenario 4 = mild + sedentary

Figure 2: Construction of scenarios

Scenarios are narratives of events that put individuals in a certain situation to observe their reaction and predict their behaviour (Camponovo et al. 2004). The advantage of this method is that it allows to integrate the general public in a study and to observe the variation of behaviour of individuals according to the values of the manipulated items. In the specific case of our study, the scenario-based approach would make it possible to include even those individuals who have not yet experienced allergic reactions to know what their reaction would be.

In addition, the challenges lie in the realism and identification of individuals to the story being told. However, a strict process for editing the scenarios would allow reducing the different negative points, hence the importance of the tests carried out throughout the process before the validation of the final scenarios. The severity of previous allergic reaction will be measured using the measurement classification developed by Ring and Messmer (1977) and Niggemann and Beyer (2015). We will use the different recognised symptoms at each level of severity. Moderate reactions often manifest as skin reactions or stomach aches; while severe reactions often manifest as respiratory problems, anaphylactic shock in addition to the moderate manifestations (Baiardini et al. 2011). Concerning the mobility context, we will represent the case of a travelling individual who often consults different doctors and a sedentary individual who consult the same doctors. We will have four scenarios that we will present to 4 groups of individuals (50 individuals per each group). Therefore, we will collect data from approximately 200 patients in a university hospital in France.

4 Expected Contributions and Conclusion

The findings of this research will contribute to research and practice. In terms of research, we will extend the privacy calculus model with specific contextual elements from a field study. In this, we see two contributions. First, the application of the privacy calculus model to study the adoption of a health application whereas this model has been used in the literature mainly in the e-commerce field (Beke et al. 2022; Scarpi et al. 2022). However, the privacy issue is one of the critical factors in the adoption of health applications (Angst and Agarwal 2009). The use of the privacy calculus in health is therefore a relevant approach to weigh different types of apps and in different contexts the risks of disclosure of personal information against the benefits of use, which can be of several kinds in health. The second aspect is the identification of contextual elements in health that allow us to extend the basic privacy calculus model, in particular the mobility context and the severity of a previous allergic reaction in our case. These contextual elements can be analysed for other diseases.

On a practical level, contextual elements to moderate the impact of perceived benefits and risks on adoption may help developers of digital health apps to better understand the patients' needs about specific features of the application. Methodologically, we aim to provide empirical evidence of the feasibility of the scenario method in the field of PHR adoption.

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