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An Action Design Research to Facilitate the Adoption of Personal Health Records: The Case of Digital Allergy Cards

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ABSTRACT

Adoption and user perceptions are dominant on personal health records literature and have led to a better understanding of what individuals' behaviors and perceptions are about the adoption of personal health records. However, these insights are descriptive and are not actionable to allow creating personal health records that will overcome the adoption problems identified by users. This study uses action design research to provide actionable knowledge regarding user perceptions and adoption and their application in the case of the digital allergy card. To achieve this, the authors conducted interviews with patients and physicians as part of the evaluation of the digital allergy card mock-up and the first prototype. As results, they provided some research proposals regarding the benefits of, levers for, and barriers to adoption of the digital allergy card that can be tested for several other personal health records.

KEYWORDS

Action Design Research, Adoption, Business Process Model, Digital Allergy Card, Drug Allergy Information, Mock-Ups, Personal Health Records

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INTRODUCTION

Personal health records (PHRs) can facilitate patient management and ensure patient safety throughout the care process (Sherer, 2014). Among the benefits often cited are the completeness, accessibility, reliability, and timeliness of health information, as well as the capacity for self-monitoring (Chaudhry et al., 2006), which has been evaluated as one of the determining factors for the well-being of chronically ill patients. More concretely, PHRs whose access is controlled by patients can be connected or not to the hospitals' electronic medical records (EMRs) (Roehrs et al., 2017). PHRs are designed and implemented to collect, process, store, secure, and share patient health information, as well as involve patients in their own care.

Research on PHRs varies and concerns various themes, such as design, functional, technical, and clinical evaluation, and adoption (Andrikopoulou et al., 2020; Cafazzo et al., 2012). The topic of adoption is dominant in the literature on medical informatics and information systems on PHRs (Greenhalgh et al., 2010; Studeny & Coustasse, 2014; Wiljer et al., 2008). Most authors have explained the adoption of PHRs using various theories and models (Laugesen & Hassanein, 2017; Vezyridis & Timmons, 2015; Whetstone & Goldsmith, 2009). The most widely used models are the Technology of Acceptance Model (TAM) and the Unified Theory for the Acceptance and Use of Technology (UTAUT), with the variables of perceived usefulness, perceived ease of use, social influence, and facilitating conditions (Blut et al., 2021; Whetstone & Goldsmith, 2009). These models have been enriched by several technological and individual factors. Among these factors, we can often find the issue of privacy, e-health literacy, health conditions, and personality traits (Li et al., 2014; Noblin et al., 2012; Xu et al., 2016). The link between these factors and the intention to use technology has been shown through quantitative studies by administering questionnaires and analyzing the data through structural equation modeling. This approach highlights the positive or negative aspects and the strong or weak impacts of these links.

All of these studies provide different levels of understanding of the determinants of adoption and users' perception of PHRs (Archer & Cocosila, 2014; Gagnon et al., 2016). According to several authors, the results of these studies should guide in the design of apps that overcome the problems they predict (Hevner et al., 2004). However, the use of those models and users' perceptions are limited to supporting the decisions taken by practitioners and providing actionable knowledge—that is, knowledge that can not only contribute to our understanding of the phenomenon itself but also "generate useful knowledge with the goal of building a better future" (Markus & Mentzer, 2014) for practitioners. This is in line with numerous recent calls in IS to develop relevant knowledge for practice (Avison et al., 2018; Baskerville & Wood-Harper, 1996; Davison et al., 2004; Jabagi et al., 2016; Markus et al., 2002). Indeed, actionable knowledge needs an understanding of the context and of users' needs and perceptions of the challenges that can be solved by a PHR, as well as intervention in a concrete case to assess and improve this knowledge.

A specific kind of PHR related to a specific context is the digital allergy card (DAC). Because the current drug allergy information process is not optimal for the transmission of the right information at the right time, the European Academy of Allergology and Clinical Immunology (EAACI) has proposed the implementation of allergy apps (Brockow et al., 2016; Khalil et al., 2011; Villamañán et al., 2011). Therefore, the goal of a DAC is to ensure patient safety by making allergy information available to make the optimal therapeutic decision. Indeed, problems with allergy information can cause serious harm, especially drug allergies, which require special attention from physicians—mostly family practitioners—when they write a prescription (Dworzynski et al., 2014; Villamañán et al., 2011). These problems can be either underdiagnosis (Ferner & McGettigan, 2020)—or overdiagnosis (Ferner & McGettigan, 2020).

Our paper follows the evidence-based information systems approach (Wainwright et al., 2018), with the aim of providing concrete evidence to enable the adoption of the DAC PHR. The objective of this paper is to provide actionable knowledge based on action design research (ADR). This method

contains several stages - problem formulation, building, intervention, and evaluation (BIE), reflection and learning, and formalization of the learning. We also use an inductive thematic analysis based on grounded theory (Corbin & Strauss, 1990) in the BIE stage to assess users' perceptions in terms of the potential barriers and benefits of a DAC. Based on this evidence, we create knowledge in the form of developing some research propositions to be tested in further studies related to PHR use.

The following sections successively present the literature review, research design, results, discussion, and conclusion, which highlight the main contributions in terms of the developed app's ability to optimize the management of drug allergies and the research propositions.

LITERATURE REVIEW

In this section, we briefly present a background of PHRs related to adoption and users' perceptions and discuss the limitations of the existing studies.

Background of PHRs

A PHR is an electronic record that individuals can use to store medical and health information for themselves, their children, or other relatives; it is also a health management tool that encourages the active participation of individuals in their health care (Gordon et al., 2012; Kahn et al., 2009; Roehrs et al., 2017). An individual can personally create a PHR by entering their health information into an app available through a company on the internet—this type of PHR is classified into the category of standalone PHR (Li et al., 2014). A second type, connected PHR, is created by a health provider or insurance company using the information that they currently keep (Detmer et al., 2008). The information stored in a PHR can include—but is not limited to—name, age, height, weight, emergency contacts, insurance information, immunizations, allergies, drug reactions, medications, illnesses, hospitalizations, surgeries, laboratory test results, and family history of medical conditions (Archer & Cocosila, 2014; Roehrs et al., 2017). PHRs involve several stakeholders (Payton et al., 2011), the main stakeholders being patients and individuals who are empowered to self-monitor their health (Gagnon et al., 2016). Physicians are also important in supporting individuals' self-management decisions (Witry et al., 2010).

The adoption of PHRs by patients and individuals is a complex issue that scholars have attempted to understand, explain, and predict through various models and theories (Abd-Alrazaq et al., 2019; Li et al., 2014; Whetstone & Goldsmith, 2009; Wu, 2016). These models have been tested by quantitative methods to identify the link between several explanatory variables and the intention to use PHRs, as well as the links between the explanatory variables themselves.

The most commonly used adoption models are the TAM and the UTAUT (Davis et al., 1989; Venkatesh, 2000). The TAM states that perceived usefulness and perceived ease of use have a positive impact on the intention to use a PHR. The UTAUT states that performance expectancy, effort expectancy, facilitating conditions, and subjective norms have an impact on the intention to use a PHR (Blut et al., 2021). Researchers have enriched those models with other factors, such as e-health literacy (Noblin et al., 2012), anxiety (Cocosila & Archer, 2018), trust (Li et al., 2014), personality traits (Xu et al., 2016), privacy issues (Zhang et al., 2018), and fear appeals (Andrikopoulou et al., 2020; Rogers, 1975).

Patients' health conditions may also be a factor in adoption, beyond the explanations of the TAM or the UTAUT (Li et al., 2014). For example, several studies have highlighted the fact that patients with chronic diseases are often more likely to adopt a PHR to help them monitor their health condition compared to individuals whose purpose in using a PHR would be to prevent emergencies or diseases (Laugesen & Hassanein, 2017). Furthermore, the adoption of PHRs by patients and physicians is not driven by the same factors (Witry et al., 2010). An important element for physicians is compatibility with existing systems, time of use, and fit with their work practice to avoid nonuse, misuse, or workarounds (Laumer et al., 2017).

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In addition, qualitative studies using focus groups or interviews have highlighted the facilitators and barriers to the adoption of PHRs. These qualitative methods capture factors that are not included in existing adoption models (Witry et al., 2010), which can be gathered into several categories related to the system, the environment, the capabilities and attitudes of different user groups, ethical and legal issues, and information (Gagnon et al., 2016; Witry et al., 2010).

Current methods, whether quantitative or qualitative, do not allow for the development of actionable knowledge to ensure that PHRs will overcome adoption problems in the specific contexts of their stakeholders. For this reason, we decided to use the Action Design Research (ADR) approach.

Action Design Research

ADR draws its theoretical foundations from research in design sciences that seeks to develop prescriptive design knowledge through the building and evaluation of innovative IT artifacts intended to solve an identified class of problems in a predefined organizational context (Costa et al., 2020; Fettke et al., 2010; Hevner et al., 2004).

The outcome of an ADR can be an artifact and the prescriptive knowledge that arises from the design process and use of that artifact (Hevner & Chatterjee, 2010). This prescriptive knowledge is often called design principles or research propositions (Gregor et al., 2020). However, because the fundamental paradigm of design science research is the resolution of a class of problems, it is crucial to evaluate the fit between the proposed artifact and the problem, especially in the organizational context in which the problem was identified and the solution was deployed (Sein et al., 2011). In ADR, the evaluation is done iteratively during the design. ADR starts from the basis that the artifact is shaped by the organizational context both during the design process and in its use after implementation (Sein et al., 2011)

The starting point of an ADR process is a practical problem in an organization (Hevner & Chatterjee, 2010). The ADR approach combines an action research methodology and the design research perspective to iteratively build and evaluate IT artifacts until a version ready for implementation in a specific organizational context is obtained (Sein et al., 2011). ADRs have two types of actors (Baskerville & Wood-Harper, 1996; Sein et al., 2011): (1) researchers and practitioners who bring theoretical expertise and practical expertise, respectively, in the construction of the artifact, and (2) end users in the organizational context who are involved in evaluating the artifact and consider improvements during the design process (Sein et al., 2011). Both types of actors are essential when deciding whether the artifact is ready for implementation.

The so-called end users are critical to the design process in validating the artifact according to their needs (Smith et al., 2020). Thus, ADR encourages these end users' involvement from the early stages of the design process to formulate the problem and help to iteratively achieve the most suitable solution.

RESEARCH DESIGN

This research project was initiated in March 2019 by an allergist and a researcher in information systems (authors of this paper). After that, a hospital allergy unit manager and researcher in allergology were involved. Both allergists work actively to manage allergic patients in a French hospital. From their experience, they identified several problematic situations relating to drug allergy information. An allergology Ph.D. student (also an author of this paper) and a technology company collaborated to design a solution for allergy information traceability.

This research was led by a Ph.D. student in industrial information systems (hosted by the technology company) according to the different stages of an ADR (Sein et al., 2011)—the formulation of the problem; Building, Intervention, and Evaluation (BIE); reflection and learning; and formalization of learning. The data were collected from patients and physicians and analyzed during the first two

phases using qualitative methods. The final two steps helped formulate the learning that emerged from the ADR process.

Context Of Drug Allergies and The Relevance Of A Digital Allergy Card

Drug allergies affect approximately 10% of the general population and are a major public health problem (Brockow et al., 2016). Indeed, among individuals who declare themselves allergic to drugs, only 20% are actually allergic (Brockow et al., 2016). However, the label "drug allergic" may be considered by the physician even when it is not accurate, or it may not be taken into account when it is true. Patient safety is involved in both cases because, in the first case, alternative drugs are often more expensive and less effective (Golden et al., 2011), and in the second case, the patient is at risk of fatal anaphylactic shock because they are being given a risky medication (Apter et al., 2004). Even when the patient has a reaction to a drug, the level of severity of the reaction may lead the physician to decide whether to continue the drug based on the risk/effectiveness ratio (Ferner & McGettigan, 2020). Therefore, allergy information must not only be accessible but also be sufficiently detailed to support the physician's decision and guarantee patient safety.

Indeed, the label "drug allergy" may limit the choice of therapeutic prescriptions for a given patient. Thus, the reliability of this label is of great importance for at least two main reasons. First, underdiagnosis (underreporting) and overdiagnosis (suspicion of allergy—for example, based only on a patient's clinical history) may lead to the readministration of a risky drug to the patient in the first case (Apter et al., 2004) or, in the second case, affect future therapeutic options that lead to the use of more expensive and potentially less effective drugs (Golden et al., 2011).

Second, drug allergies make up one category of drug hypersensitivity reactions (DHRs). DHRs may be classified into several other categories based on two main factors: the immunological nature and the severity of the reaction (Ferner & McGettigan, 2020). Depending on this classification, different therapeutic decisions may be made. The label "drug allergy" itself corresponds to immune reactions, and in cases of low severity and lack of proof (i.e., no allergy work-up), a physician may decide to override this label instead of prescribing a less effective alternative drug (Ferner & McGettigan, 2020).

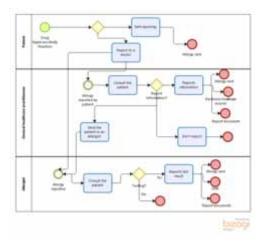
Therefore, the documentation of a drug allergy should be sufficiently detailed and allow for proper classification to help the physician make optimal decisions for the patient. Indeed, the poor clinical documentation of drug allergies and the inability of clinical information systems to capture the difference between adverse drug reactions and drug allergies are the main problems of drug allergy diagnosis and management (Dworzynski et al., 2014).

The availability and accuracy of allergy information are key for patient safety related to drug prescription and administration (Huckvale et al., 2010). However, current solutions that make allergy information available consist of verbal communication from patient to physician, which is limited when the patient is unconscious; paper cards, which can easily get lost; and drug allergy reports, which are held in a hospital's EMR, which is not accessible to other hospitals (Nguewo Ngassam et al., 2020). In this context, the European Academy of Allergies and Clinical Immunology (EAACI) advocated for the creation of a digital app to trace drug allergies (Brockow et al., 2016). Indeed, a PHR for drug allergies could improve existing systems in terms of the completeness, accessibility, and accuracy of information through features that enable the technology to overcome the weaknesses of current solutions (Huckvale et al., 2010).

Stage 1: Problem Formulation

The project team presented above formulated the problem and the solution during three face-to-face team meetings and a dozen email exchanges. At the end of the face-to-face meetings and email exchanges, the current health care processes regarding allergies in France became apparent, as described by the allergists. Figure 1 illustrates the business process model (BPM) for health care processes regarding allergies. A BPM is a graphical representation of how a use case is or should be carried out. It is a tool for process management that allows for the automatic planning, simulation,

Figure 1. Process of clarifying drug allergy information



and execution of processes (Lin et al., 2002; Qingzhong et al., 2003). The project team used Bizagi software to design this BPM.

When an adverse drug reaction occurs, the patient may ignore the information, self-report, or share the information verbally with a physician. The physician can either directly consider the information given by the patient, ask the patient further questions, or test the patient to ensure consistency and the possibility of an allergy. The physician can then ignore the information by not reporting it, record the information in the internal EHRs, draw up an allergy card, or suggest that the patient have a consultation with an allergist for evaluation and testing. The allergist may or may not test the patient; in the case of testing, they may either report the test results in the EHR or establish a paper card. Regardless of the situation, the information on the allergy, when it exists, must be shared with the physician to prevent the administration of risky drugs to the patient (Brockow et al., 2016).

We conducted a BPM of the health care process regarding drug allergy information to identify the weaknesses of this process. The first aspect that became clear is that there are several ways to store allergy information, which can make the patient record more cumbersome. The second aspect we uncovered is that allergy information can be lost or inaccessible to a physician who needs it at any time in the process. We argue that a mobile app (in this case, the DAC) would simplify the process for both physicians and patients by standardizing the storage and accessibility of allergy information.

The description and analysis of the process highlights the following specifications:

• There are three groups of users: patients, physicians, and trusted third parties.

Based on the literature on patient empowerment (Avelino et al., 2017; Vezyridis & Timmons, 2015), the project team decided that the patient was the owner of the data and could make the data accessible to physicians. The patients also choose trusted third parties from their relatives to act on their behalf.

- The patient, physicians, or trusted third party can report an allergy reaction.
- The information can be labeled "self-reported," confirmed, or denied. The first label is for allergy data that are not validated by a physician. For the last two labels, the physician has to edit the data and specify the validation procedure.
- The patient has total control of their data and has the right to grant access or not to other users.

- The patient chooses their trusted third parties to manage access rights in case of their unavailability.
- The physician can urgently access a patient's file if the patient cannot grant them the rights and they are not able to reach any trusted third party.

These specifications were then sent to the developer in the form of diagrams and models.

Stage 2: Building, Intervention, And Evaluation

This stage includes modeling the solution, developing the application, and presenting the user assessment.

Solution Modeling

Starting from the BPM and the specifications identification, we moved to the technical modeling phase using a specific technique called the Unified Modeling Language (UML), which is a general-purpose developmental modeling language for analysis in the field of software engineering. The UML is intended to provide a standard way to visualize the design of a system (Lee, 2012)—for example, by designing a class diagram that describes the data structuring and sequence diagrams, which are the description of each use case of an app.

We used Argo UML software to model the class diagram, the use case diagram, and the sequence diagrams for each use case to move from user language to technical language, which is easily understood by developers (Medvidovic et al., 2002).

After the analytic phase, the authors designed interactive mock-ups (see Figure 2) with the web app Balsamiq Cloud (https://balsamiq.cloud). The mock-up shows the appearance and content of each page and the general plan of the app. This makes it possible to present an aspect of the application to users without having to actually code the interfaces. While diagrams generally represent the back end of the application, mock-ups allow for the representation of the front end—i.e., the layout of the functionalities, tabs, etc.

After designing the mock-ups, we carried out a first round of evaluation with six patients, in line with the ADR recommendations.

App Development

The feedback of the first evaluation round in terms of content and ease of use enabled the development of the first prototype of the app. This version of the app was assessed during a second round of interviews with patients and physicians. The DAC that we designed and developed in this study (see Figure 3) is a hybrid app (i.e., a mobile and a web version). Therefore, it can be accessed from a web portal or directly through the app downloaded on a mobile device.

Apart from the identification and authentication process, the DAC has three main features. The first feature is the reporting of allergy information, which can be completed by the patient, an

Figure 2. Interactive mock-ups

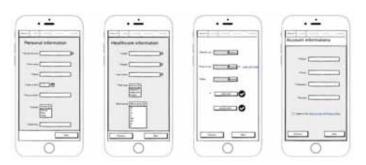


Figure 3. App interfaces



authorized physician, or a trusted third party chosen by the patient. A color code (similar to a stoplight) was implemented to visually suggest the level of confidence given to the allergy information. When an entry—irrespective of whoever declares it—is not confirmed by a physician, it remains in the self-reported information category, represented by the yellow color ("suspected, not confirmed").

The second feature allows a physician to confirm or refute the presence of an allergy by studying the patient's history or by conducting allergy tests. The green and red colors, respectively, represent the "suspected, confirmed" allergies and those that are "suspected, ruled out" after validation by a physician. The third feature allows patients to grant access to specific users. This refers to giving access to physicians and trusted third parties. This access must be authorized in advance by the patient, except in an emergency (i.e., when the patient and trusted third party are unable to grant access), during which the physician may override the patient's rights to manage the emergency.

This app is connected to a private permissioned blockchain to ensure strong traceability of information on drug allergies. Private blockchain is a partially decentralized and permissioned distributed ledger that allows for the control of data by an identified group of actors in a secure and reliable environment rather than by a single organization, as in centralized systems (Agbo et al., 2019). Therefore, the blockchain ensures the transparency, privacy, and reliability of information at the same time.

Allergy information management is of public interest because all individuals can be affected (Demoly et al., 2014). However, aside from the allergists who were involved in the needs assessment, public opinion is largely unaware of the DAC's specification. Heeding the recommendation of prior research to involve end users in the design stage of the project to better identify user needs and design an ideal solution to fit the day-to-day lives of users (Smith et al., 2020), we conducted a user assessment for the DAC with patients and physicians. The purpose of these user assessments was to clarify the needs and opinions of users on the different versions of the application and thus improve the DAC in an iterative way according to the principles underlying the BIE stage—reciprocal shaping, mutual influential roles, and authentic and concurrent evaluation (Sein et al., 2011).

Data Collection and Analysis

Data were collected by semistructured interviews during the two evaluation rounds. The first round of interviews was conducted in July 2019 for the mock-ups, and the second round was conducted in August and September 2019 for the prototype. Sixteen interviews were conducted with a convenience sample of five physicians and 11 patients at a French University Hospital.

The procedure to conduct the interviews was performed as follows. The two Ph.D. students on the project conducted the interviews, starting with asking open-ended questions on the personal context of the interviewees and on topics such as drug allergies, the allergy card, and their understanding of a DAC. Then, they presented the mock-ups of the app to be evaluated and asked the interviewees to use them and make remarks according to the "think-aloud" method (Watbled et al., 2018). Finally, another phase of questioning was initiated to allow respondents to express their individual perceptions related to the utility, ease of use, and content of the app, as well as their intention to use it. To ensure

consistency in data collection, the interviews were performed by the two Ph.D. students together. Interviews were audio taped and transcribed.

Our data analysis consisted of analyzing potential users' answers to the interview questions, as well as their comments during the manipulation of the mock-ups and DAC prototype. Based on the transcribed interviews, relevant themes were inferred by two members of the project team separately and from different transcribed interviews (one for patients and one for physicians) using an inductive thematic analysis, which was inspired by grounded theory (Corbin & Strauss, 1990). All interviews and "think-aloud" comments were assessed with a first code close to the respondents' words. Then, a more general coding was performed. The resulting coding scheme was discussed with two other authors of this paper. Disagreements were discussed until a consensus was reached (Zwaanswijk et al., 2011). Later, we interpreted the results by analyzing the links between the different interview data.

RESULTS

In this section, we report the last two stages of the ADR process: reflection and learning and the formalization of the learning.

Stage 3: Reflection and Learning

DAC Content

For patients and physicians, the DAC represents an app containing identity information and the details and validation status of allergies. In addition, according to patients, the DAC could also contain practical guides for patients with drug allergies.

DAC Usefulness

In terms of usefulness, the DAC would allow for more complete and better retention of allergy information. In fact, patients advocated the fact that, with a digital tool, it would be possible to record more information than on paper and that this information would be better stored using a digital database. Moreover, allergy information would also be made more accessible through the DAC, allowing physicians to use it to make therapeutic decisions in relation to a patient's case. Another important function of the DAC is proof of information, in the sense that it will be possible to know whether an allergy reported by a patient is actually confirmed by a physician. The last aspect of the usefulness of the DAC that emerged from the interviews is the communication between patient and physician. However, this point of view is not shared by some patients, as one expressed her difficulty contacting physicians because of their busy schedules.

Facilitators for the Adoption and Use Of The DAC

For patients, the facilitators for adoption and use may be related to a previous bad allergy experience—for example, patients who have already experienced a severe allergy reaction will be more likely to adopt the DAC, which could help them better manage future allergic reactions. In addition, a strong recommendation from the physician could incite some patients to adopt and use the DAC.

For physicians, the main leverage is the fact that patients already use the app, so they are sure to find the information they need concerning a specific patient.

Barriers to The Adoption and Use Of The DAC

The first barrier is related to the ease of use of the app. If the accessibility of the DAC is difficult, some users will be discouraged from adopting it. In this sense, the ergonomics and the process to be followed have to be very simple to minimize the complexity as well as the time of use.

Table 1. Thematic analysis: coding process

| Quotations | First code | General code |
|--|--|--|
| " Containing especially personal information (surname, first name, date of birth), the type of drug or food allergy. In addition, of course, specify the molecule. Already have many details on allergen." – Patient 5 "I will just put Allergies and then whether it is validated or not by the physician." – Patient 8 | The DAC should contain patients' identity information and details about the allergy | Representation of the content of the DAC |
| "I told you a little while ago, guidelines for each child. Additionally, what you have prescribed for us in case he has an allergic reaction". Patient 1 | The DAC should provide medication guidelines to patients | |
| "The disadvantage of a paper card is that you can lose it, while the digital one, if it is on the phone, very often you do not lose the phone and we always have it on us, and it is easier to get the info every time you need it." – Patient 4 | The DAC allows for better storage of information compared to paper records | Usefulness |
| "If the database is dematerialized, then we can access it directly so it's interesting." – Patient 2 $$ | Allergy information is dematerialized by the DAC | |
| " If I make the parallel, for example, with regard to vaccinations or that we do not have the health record, etc. To prove that we have had the vaccinations, it is not always easy, or we can lose the vaccination card; if we had the same thing for vaccinations, it would be perfect, I think, in the end I am for the computerized medical record." – Patient 2 | The DAC provides proven allergy information | |
| "He contacts me directly, within the hour." – Physician 1 | The DAC allows for fast patient/ physician communication, usually within an hour | |
| "This app can guide me to inform differential diagnoses." – Physician 2 | The DAC allows for better orientation of the clinical diagnosis | |
| "I think that after me, since I was late, that I have a very important allergic reaction, suddenly this is something that scared me a little, so I think that with this app, yeah, we did get in touch directly with the physicians, being able to get answers fairly quickly, all that I think is good." – Patient 3 | A negative experience with allergies can lead to the use of the DAC | Facilitators of adoption and use |
| "If it came from the physician, yes." – Patient 1 | The physician's recommendation can be an incentive to use the DAC | |
| "I think, at first I will not use it much, as I do not know if the patient is registered, or he is not registered. However, if for example, I find that 40 to 45% of people are already registered, yes." – Physician 3 | The fact that patients use it will make it easier for physicians to use it | |
| "Yes, but not even that. I have a problem I have my family physician, and I have my pulmonologist who follow me regularly since I have a problem with my heart." – Patient 5 | The DAC has a low perceived utility | Barriers to adoption and use |
| "However, slightly like the shared medical file, but it should be even easier to access than the shared medical file The goal is that." – Patient 8 | The app should look and be more accessible than existing apps, such as the shared medical file | |
| "There will never be time to do this in consultation, in 15 minutes, it is not possible! For the first time, no one will do it." – Physician 5 | Too long of a registration time can discourage physicians from using the DAC | |
| "For me, ergonomics in the space of half an hour, it will be very easy, but imagine someone who is 65 years old after 5 minutes, it is enough, the phone goes through the window." – Patient 8 | Depending on the age group, ergonomics can be a barrier | |
| "I think of an emergency measure to say when we connect in the summary is that there should be immediately the allergy that initially appears in fact." – Patient 2 | Produce a list of allergies at the home page | Suggestions for DAC improvement |
| " However, we can do it for the expert version, in fact you can do it as an underlying and access it in the expert version. A simple version and an expert version would be ideal." – Patient 8 | Make two versions of the app (a simple one and an expert version) | |
| "Let's say this is a patient, could he take in the medicine several times? Why not register on the same tab of the drug? Or do you actually do it by reaction or by drug?" – Physician 4 "He should be able to put an episode on the same page. Therefore, we have all the follow-up for the same drug." – Physician 5 | Classify the allergy list by allergen or drug rather than by episode of reaction | |
| "And then, for example, for cutaneous tests and everything you can take pictures of them? For the results?" – Physician 4 | Integrate the scan of cutaneous test results | |

Suggestions for DAC Improvement

Patients and physicians made some suggestions for improving the DAC to facilitate its adoption and use.

First, patients suggested improving the classification and visibility of allergy information in the app. They proposed that allergies be classified by allergen with a history of all reactions for the same allergen, contrary to the classification that had initially been made (i.e., by reaction). In addition, to guarantee this ease of use, patients suggested the creation of two versions of the app: a version with basic features (allergies and validation status) and a complex version that allows the input of more information, depending on each user's level of comfort with the technology.

Some of the interviewees suggested that important information should be directly visible when the app is launched. Specifically, the home page should clearly identify the lists of allergies. They also proposed adding proof of the tests (i.e., scans of the results) when the information was validated.

This feedback from the interviewees allows us to modify the application.

Stage 4: Formalization of the Learning

As presented above, the DAC is a PHR for allergy information. This is justified by content, form, and purpose. Through the interview data, we can note that the DAC has many characteristics that allow it to be equated with a PHR, so the DAC appears to be a representation of the PHR class. Therefore, we use the results of the present study to make some proposals to be tested or implemented in other PHR contexts.

DISCUSSION

The purpose of this study was to provide actionable knowledge for the development and promotion of PHRs using an ADR interventionist method. Using this method, we built a DAC based on a collaborative project related to a ground medical problem (lack of accessibility, completeness, accuracy, and traceability of allergy information) identified in the medical literature (Chiriac et al., 2019; Khalil et al., 2011; Villamañán et al., 2011).

The evaluation round conducted during the BIE stage highlighted potential user benefits of, facilitators for, and barriers to a specific PHR. The specificity of the medical context (drug allergy) and the newness of the DAC make it difficult to apply existing models and theories such as the TAM (Whetstone & Goldsmith, 2009). Indeed, while the TAM shows that perceived usefulness has a positive impact on the intention to use a PHR, it is still necessary to empirically identify these benefits for the specific case of the DAC, which can be conducted through qualitative studies (Fox & Connolly, 2018). Then, it is necessary to be able to apply this to a PHR by developing features that will allow users to take advantage of these benefits in a concrete way by iteratively improving them according to the stakeholders' feedback. In this context, our pragmatic study (Smith et al., 2011) aims to provide actionable knowledge to PHR promoters. For example, in our case, some patients and physicians identified the proof of allergy information as a potential benefit of the DAC; therefore, we integrated some features in the specifications to allow physicians to validate information about an allergy after a cutaneous test or another appropriate clinical procedure.

The evaluation with patients and physicians highlighted several aspects that make the DAC similar to a PHR. The main factor is the accessibility of allergy information, which patients and physicians assert is a very important function of the DAC. This is also the first recognized benefit of PHRs (Vance et al., 2015; Zwaanswijk et al., 2011) because these tools enable the accessibility of health information, allowing for the improvement of patient safety (Tang et al., 2006). Allergy information helps physicians make informed therapeutic decisions for prescriptions or the administration of treatments. Among existing solutions to make this information available, there is verbal communication, which can be hampered if the patient is unconscious, for example; reporting in isolated EMR renderings, where information may not be accessible to other physicians; and the paper card (Roehrs et al., 2017) that

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can enable the same level of accessibility if patients always keep it with them. However, the paper card does not provide enough information on the allergy, especially in terms of test validity, and it can easily be lost. Moreover, the accessibility of information seems all the more crucial in emergency situations such as accidents.

Access to the DAC by the physician can be achieved by two methods. The first is directly on the app by creating an account and authorizing access by the patient whose file the physician wants to consult. The second method is directly on the physician's workspace. This solution facilitates access in a short time. Indeed, to enable physicians to perceive the benefits of information accessibility, this accessibility must be easy and fast in cases of emergency and avoid wasting time during consultations, which are often very short. In this context, the solution of interoperability with existing systems seems ideal to avoid increasing the number of tools used by physicians to ensure continuity of care (Dobrow et al., 2019) regardless of the health institution that manages a patient. This is important because one of the barriers to the adoption of the DAC mentioned by physicians is the time it takes to access the information in the e-health application. Indeed, given the short consultation time that physicians have with their patients, it is often not possible for them to navigate through several tools.

Furthermore, beyond the accessibility of drug allergy information enabled by the DAC, physicians are concerned about the accuracy of this information. In the case of drug allergies, physicians want to ensure that the allergy information has been confirmed by tests to avoid incorrectly prescribing alternative drugs that are often more expensive and less effective (Golden et al., 2011).

In short, as with PHRs, patients and physicians value the accessibility of health information through the use of the DAC. Contrary to the issue of information security and privacy, which is very often highlighted in studies on PHRs (Archer et al., 2011; Roehrs et al., 2017), the evaluation feedback does not mention these elements, aside from one patient who briefly raised the issue of information privacy in the sense of ensuring that access to information on the app would be controlled by patients. Other technical information security issues related to hosting, intrusion, or loss of data were not mentioned. This can be explained by the fact that the interviews were conducted in a trustful context, made up of allergists whom the patients trusted. This may also be explained by the fact that the privacy risks were outshined by the perceived benefits to patients. This would be consistent with the privacy calculus perspective in the literature (Li et al., 2010), which suggests that individuals compare the risks related to privacy with the benefits they could obtain from the use of an online service.

As a PHR, the DAC focuses on patients' empowerment in the self-monitoring of their health (Roehrs et al., 2017; Tang et al., 2006). This is because patients can use the DAC to manage emergency situations by following the guidelines that patients suggested should be integrated into the app according to their feedback. However, our evaluation has shown that this empowerment is not important for some patients; rather, they prefer to rely on physicians to manage the processing of allergy information. This contrast can be explained by differences in patients' preferences (Vance et al., 2015). Indeed, some patients are independent and wish to participate in their care, while others prefer the physician's intervention and support.

Another adoption factor for patients may be related to their previous bad experiences with an allergy reaction. This explains why PHRs are more accepted by chronically ill patients (Roehrs et al., 2017) or, more generally, by people who want to avoid uncertainty in cases of emergency (Hwang, 2005; Vance et al., 2015).

One specific characteristic of DAC is that its use depends on the uncertain occurrence of an allergic reaction, unlike some apps that are useful for the daily management of chronic diseases or apps that collect routine life data about health behaviors on a periodic basis (Roehrs et al., 2017). This characteristic makes the context of use a crucial factor in the decision to adopt and use the DAC and, more generally, PHRs that depend on the occurrence of the disease episode. This consideration emphasizes the fact that the context can accentuate or moderate the perceived benefits and impact the intention to use a PHR (Angst & Agarwal, 2009).

Therefore, we suggest that it is important to study the adoption of PHRs not in a general way but rather to study the adoption of a well-defined category of PHRs. Currently, there are no clear typologies of e-health applications aside from being based on the actor controlling access to the information (Archer et al., 2011). This classification has helped, for example, to distinguish EMRs from PHRs, and it has influenced adoption patterns in the sense that physicians, who are the main users of EMRs, have different goals and needs than patients, who are the main users of PHRs (Payton et al., 2011). Previous literature has placed an emphasis on adoption by the patients involved (Ford et al., 2006; Laugesen & Hassanein, 2017; Mantzana et al., 2007). More generally, the literature on information systems distinguishes between utilitarian and hedonic applications, which has an impact on the perception of utility and the decision to use the application (Kim & Hwang, 2012). Given that the use of apps such as the DAC remains preventive and implies a use dependent on the occurrence of an uncertain event, it would be interesting to build a categorization that takes into account all the implications in the measurement (that is, the scales) of perceived benefits and use.

On a practical level, this research responds concretely to the various weaknesses of existing solutions regarding the processing of drug allergy information. With the proposed solution, we suggest a new process for the allergy information circuit, which is currently fragmented between several systems.

Our research contributes to the current literature by providing actionable knowledge for the design and adoption of a DAC. We have made several proposals in terms of the benefits of facilitators for and barriers to adoption that can be tested in other adoption studies or PHR design projects. The first proposal is that patients and physicians influence each other in the decision to adopt a PHR. While physician recommendation is an important lever for DAC adoption, the number of patients already using this PHR could have a positive impact on physicians' intent to use. Moreover, we also found that the adoption of a DAC could depend on the context. The context refers to all the elements (time, place, event, and person) surrounding the individual when using the service. Another proposal is that PHRs should integrate features to ensure the accuracy of health information, as the evidence of information is based on the benefits of health information.

CONCLUSION

This study described the design process of a DAC and analyzed users' perceptions regarding the usefulness and ease of use of the DAC, as well as the facilitators for and barriers to the adoption and use of the DAC by patients and physicians. We used ADR, which allowed us to intervene in a concrete way to improve the DAC based on the comments of the interviewees, rather than doing it in a general way to obtain general knowledge that is not necessarily actionable.

We found that patients and physicians see the DAC as a PHR with the capability of addressing issues related to the availability, completeness, accessibility, accuracy, and reliability of the information. Elements such as the prevention of emergency, the severity of previous experiences with allergies, or the expectation of the physician's opinion before using the app appear to be facilitators for the app's use, while the complexity of ergonomics and extended time of use emerged as barriers to the adoption and use of the DAC. We used this feedback to improve the subsequent version of the app.

The main limitation of this study is related to the size of the sample and the level of detail in the interviews. We conducted the interviews in a hospital in France with patients who came for tests in the allergology unit, and we had just enough time between the two interventions to talk to them. For this reason, we were not able to go into more detail on some of the themes mentioned by the interviewees, and there was also a surprising absence of certain other themes. More specifically, future studies could further analyze new adoption factors such as the context of use and the reciprocal influence between patients and physicians.

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