Analysis of the design, evaluation and the adoption of a personal health record

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« L'Université n'entend donner aucune approbation ni improbation aux opinions émises dans cette thèse ; ces opinions doivent être considérées comme propres à leur auteur. ».

I dedicate this work to my lovely parents

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Acronyms

DAC: Digital Allergy Card

PHR: Personal Health Record

EMR: Electronic Medical Record

EHR: Electronic Health Record

AIM: Association Information Management

ECIS: European Conference for Information Systems

AMCIS: American Conference of Information Systems

R&D: Research and Development

EFMI: European Federation for Medical Informatics

STC: Special Topics Conferences

DITE: Digital Innovation, Transformation and Entrepreneurship

AIS: Association Information System

SIG: Special Interest Group

CPR: Computer-based Patient Records

TAM: Technology Acceptance Model

UTAUT: Unified Theory of Acceptance and use of Technology

DSR: Design Sciences Research

ADR: Action Design Research

UML: Unified Modelling Language

DAD: Drug Allergy Documentation

BIE: Building, Intervention and Evaluation

BPM: Business Process Modelling

EAACI: European Academy of Allergology and Clinical Immunology

IT: Information Technology

DP : Design Principles

BISE : Business & Information Systems Engineering

TIS : Trusted Identification Service

P2P: Peer to Peer

DHT: Distributed Hash Table

KAD: Kademlia

WHO: World Health Organization

DHR: Drug Hypersensitivity Reaction

GDPR: General Data Protection Regulation

TRA: Theory of Reasoned Action

TTF: Task and Technology Fit

KYC: Know Your Customer

CAIS: Communication of the Association for Information Systems

JOEUC: Journal of Organizational and End User Computing

RD: Règle de Design

PD : Principe de Design

DPS : Dossier Personnel de Santé

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Foreword

Before introducing the purpose of this thesis, I would like to present some key elements that motivated and impacted me in my journey before and during the project.

1. Personal context of the researcher

First, I began a research journey with my master's thesis which had as its main motivation solving a field problem in an insurance company. From there, I became more and more interested in field problems and the potential contributions of information systems in solving these problems. After a few months between my job in a startup and some small research projects, I was frustrated.

Indeed, I was under contract with a startup in Cameroon that was developing a social network for businesses. After more than a year of activity, it was impossible to consider the marketing and profitability of the proposed service. This is just one example of several attempts to market mobile and web applications in this country. Another example is the case of the multinational e-commerce company Jumia, which closed its doors in my country two years ago because the market was unreceptive. Among other things, problems persisted relating to internet access, payment methods, and trust issues. There are several other examples of failure in disparate areas. These failures stem from various technological and socio-economic factors. I had come to consider that all these failures were related to the particular characteristics of several African countries with extremely low standards of living and low access to technology.

Healthcare experiences the same problem, whether it concerns hospitals' software or the individuals' apps. Startups have a hard time getting apps to market and launching them. Digital transformation in companies, administrations, and individuals is still at a very early stage. As a young graduate in information systems management, it was a frustrating limitation to work in such an environment.

I started my thesis in late January 2019 by contracting with a startup in France to explore the use cases of blockchain in healthcare. This company, called Pikcio, was developing a private blockchain called the Pikciochain and had started its activities in the field of banking with a unique customer identification system by integrating the blockchain for the process "Know Your Customer" (KYC). They had also started a browser project to guarantee the security and privacy of Internet users. At the time I joined this company, it was in its fifth year of research

and development (R&D). When the managers of the company heard about my thesis project, they were very interested because it aligned with their development plan, i.e., to apply their technology in healthcare. Therefore, my thesis had a pragmatic purpose integrated in the development plan of the host company.

As a PhD student in information systems, I had to contribute to the company's projects covering the field of blockchain in health.

I was excited to dive into a different universe where it would be very simple to bring a new app to market, especially with an emerging technology like blockchain. The reality hit me in the early months of my thesis when looking for use cases. I was confronted with the fact that it is also difficult in France, as it is in Cameroon, to put an app on the market, although the challenges differ.

With this in mind, I started to explore the cases we had identified until some were completely cancelled before being really launched, and the case we started was suspended due to several internal problems.

Initially, the motivation to work on blockchain was the surprising lack of real use cases for blockchain in healthcare to demonstrate its feasibility. Unfortunately, during the thesis, the company had to suspend the project I was working on because it was going through some financial difficulties that eventually led to its closure in late 2020.

Thus, our focus shifted slightly away from blockchain to user perceptions to facilitate understanding of needs and adoption of the application. However, a small part of the work shows the path of integration of blockchain as we had started it.

Later on, I became familiar with other health applications, and I noticed with regret several withdrawals of apps from the market—for example, the app of Microsoft HealthVault that was taken out of the market in 2019 because it “suffered from a slow adoption.” This app withdrawals has been linked to the failure to meet patients' needs and expectations and socio-technological constraints.

Thus, this thesis began with an enthusiasm to explore something new and was followed by a desire to capture part of a larger problem related to the design and the adoption of personal health records in the market.

First, the enthusiasm came from my previous environment where apps in general and health apps particularly are not used despite many attempts. After stepping back, I realized that part of this enthusiasm derives from a desire to satisfy my curiosity and maybe capture some strategies for app marketing in my country.

Secondly, because I was struck by the situation of health apps in France, I wanted to understand why, despite all the technological evolution, many marketing trials, and many research works, personal health records still have a limited adoption by individuals.

Overall, our experience with this thesis was a good one; it came with some difficulties but also some very rich lessons.

2. Experience in industrial contract research

The industrial PhD imposes a double challenge to the researcher who should contribute to the literature in his field while also bringing concrete solutions to the problems of the host company.

In this section, I talk about my experience in the company since, throughout the document, I focus on the research papers that constitute my thesis.

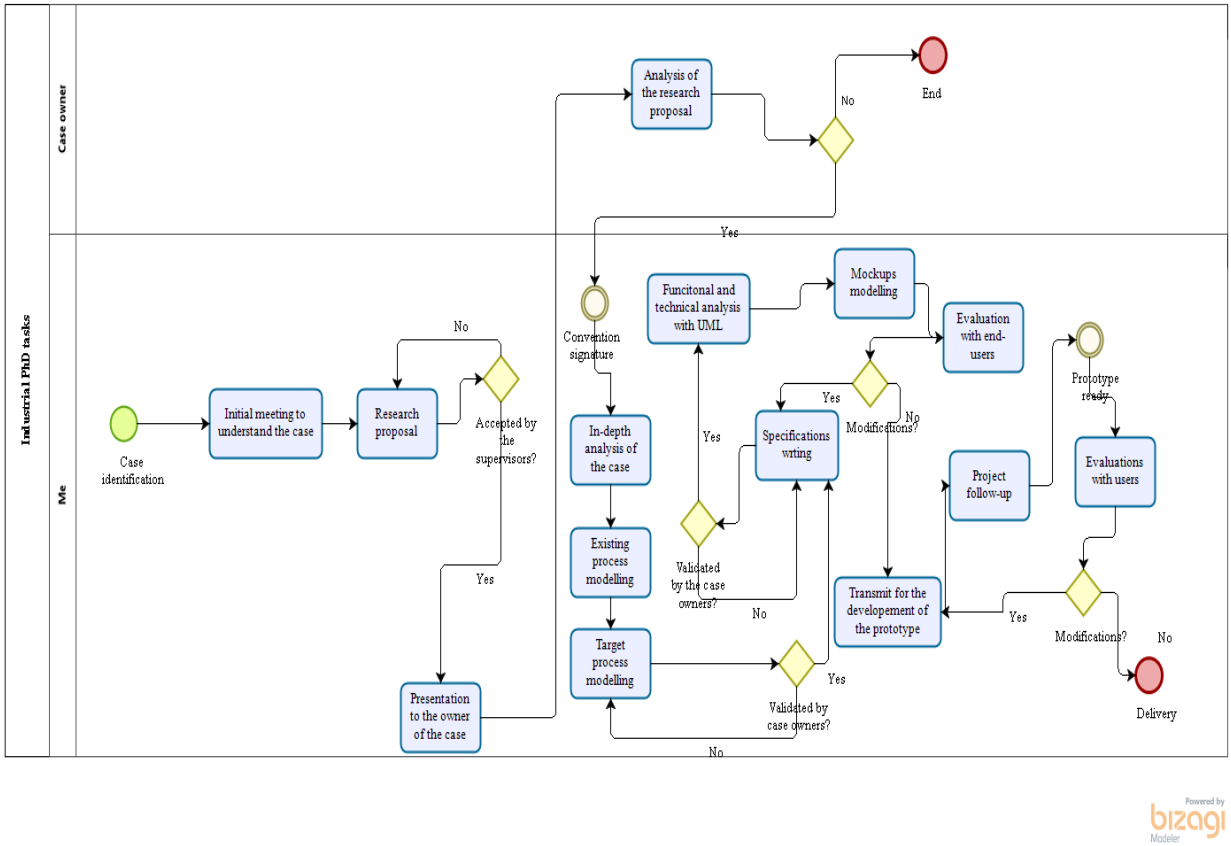
In the enterprise, I worked exclusively on healthcare blockchain projects. My tasks consisted of researching use cases, setting up the project and making the first presentations to potential partners, analyzing the existing situation, analyzing the needs, modeling the solution, and evaluating the solution with users (see Figure 1).

I was working on these tasks in very close collaboration with my company supervisor and my thesis supervisors before the project was launched. When a project started, the partners with whom we were developing the project joined the team for their specific project.

For finding projects, we exploited the direct and indirect contact networks of the company and the PhD supervisors. The direct networks were initially the professional and research relationships or those within the framework of the courses. For example, the project that we used as a case study during the thesis started from a university graduation project that brought an allergist into contact with one of my thesis supervisors who was teaching the course. The indirect networks came from people who had heard about our research project from our directs contacts.

Once a case was identified, we had a meeting with the project partners to better understand the project. Then, I was in charge of preparing a presentation and a research project to show the contribution that blockchain could have on the project. If the presentation went well, then a further study of the existing system was scheduled to clearly identify the need before moving on to the modeling and development phase, knowing that intermediate presentations to the partners and evaluations with end-users would help improve the solutions.

Figure 1. Industrial PhD experience in the host company



The analysis of the existing situation was either in the form of interviews or direct observation of the people concerned. Subsequently, the interview and observation feedback was transformed into a textual process and a diagram for better visualization. Afterwards, an optimized target process was also built with the integration of the blockchain. For the projects where the target processes were accepted, we started the functional and technical analysis using the Unified Modelling Language (UML) and the modeling of the interfaces using the "balsamiq mockup" tool, which allowed us to build the interfaces and to have a first interactive idea of the content of the proposed application. The idea behind making interactive

mockups was to be able to make a first evaluation at a low cost with users so that their feedback could be more relevant for the development of the first prototype.

The feedback from the mockups was used to adjust the specifications before sending them to the developer. At the same time, I was following up on the different projects to ensure that the deadlines were respected so that, during the planned meetings, a step of the project would be completed.

Once the first prototype was developed, we initiated another round of evaluation with end users. We had identified a total of six (6) use cases: unique identification of physicians and patients at the University Hospital, informed consent of the patient with EDOP[1], patient consent and clinical research with the cancer institute, health insurance reimbursements for self-medication, and tracking of drug allergies. Unfortunately, for the majority, these cases have stopped at the stage of reflection and ideas. Only the projects concerning the tracking of patient and clinical consents and the one concerning the tracking of drug allergy information went further. The one concerning the consent stopped after the study of the existing one because of the lockdown during the covid'19. The one concerning drug allergies reached the level of development of the first prototype. Throughout the project for the digital allergy card, I collaborated with the allergists of the allergy unit of the University Hospital of Montpellier and more particularly with one of their doctoral students who works on the clinical part of the application. Moreover, a clinical study is being prepared for the continuation of the project. This project was even submitted to the European H2020 prize, where it was selected among the 28 finalist projects of the competition.

Therefore, the unique case of the digital allergy card that we detail from several angles in this paper stems from the fact that it was the only project we were able to conduct to an extended degree.

In the rest of the document, I present all the scientific knowledge that I could get from my doctoral project.

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1 EDOP is a startup that has brought to market a platform for managing informed consents and consents for clinical studies.

General introduction

The theme of this work focuses on the design, evaluation, and adoption of a health app that we classify as a Personal Health Record (PHR).

We propose in the first part of this introduction a history of health apps from Electronic Medical Records (EMRs) to PHRs, showing the elements that favored the introduction and the expansion of PHRs. In the second part, we present the state of art in the literature and in the practice of PHRs. In the third and final part, we propose the relevance of the research context, then we present the different research questions, the methodological framework, and finally the general structure of the thesis and the organization of the doctoral work.

1. From EMRs to PHRs: A shift to patient centeredness

Prior to the 1960s, all medical records were kept on paper and in manual filing systems. Diagnoses, lab reports, visit notes, and medication directions were all written and maintained using sheets of paper bound together in a patient's medical record (Kim et al., 2011). Those records were labeled using the patient's last name, the last few numbers of the patient's social security number, or some other chart numbering system. The records were then filed and retrieved from specially made shelves designed to hold vertical file folders.

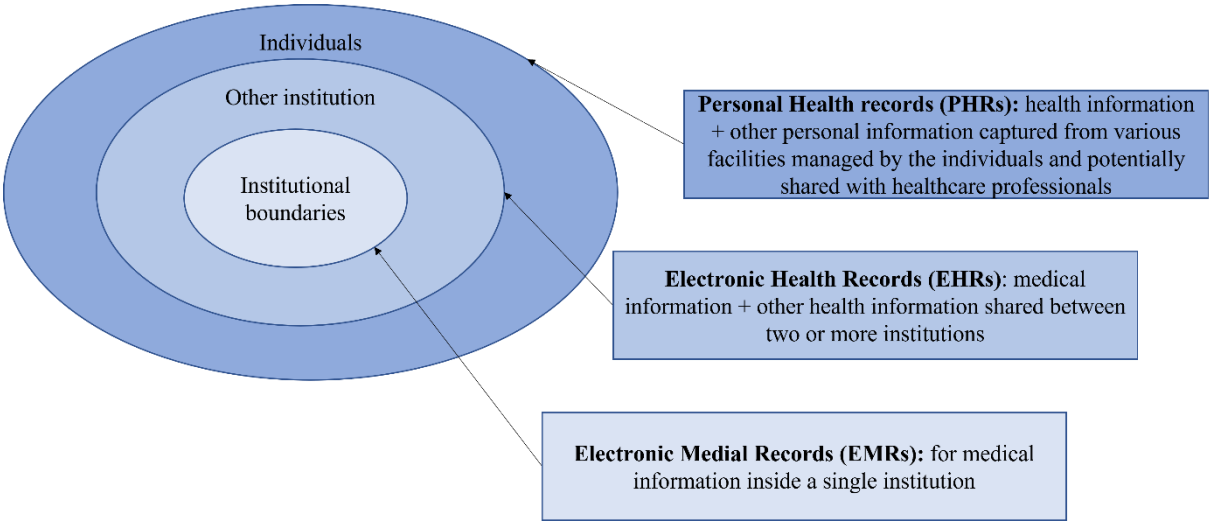
In 1972, the first EMR, known as the clinical information system, was developed by the Regenstrief Institute. This was the beginning of the computerization of health information.

EMRs refer to the digital records of patients' medical information that allow others to trace this information over time, automate patient follow-up, and generally improve the quality of patient care. The term EMR is often used interchangeably with the term Electronic Health Records (EHRs)[2]. However, the two are distinguished by the domain of access. While EMRs are only accessible within the confines of one facility, EHRs are intended to go beyond that to allow for the continuity of care across multiple healthcare facilities. In addition, EHRs include health information in a broader spectrum than EMRs (see Figure 2).

2 https://www.healthit.gov/buzz-blog/electronic-health-and-medical-records/emr-vs-ehr-difference

In 1991, a book titled *The Computer-Based Patient Record: An Essential Technology for Health Care* shook the industry out of complacency and helped drive the adoption of EHRs by breaking down all the challenges associated with the technology. A revised edition was published in 1997[3]. This book introduced EHRs as "computer-based patient records" (CPR). It was the first time an electronic patient record was viewed as a clinician's assistive technology rather than a basic mirror of old-fashioned paper records (Dick et al., 1997).

Figure 2. Evolution of health software



The advances of the Internet and information technology have greatly impacted the evolution of EHRs so that the backup of information is no longer local but on the cloud, allowing remote access, and for the features to evolve to the point of automation and the integration of these features to have an all-in-one software beginning in the 2000s (Kim et al., 2011).

The EHRs then integrate four subgroups of functions. The first concerns medical action, including information from consultations and clinical and laboratory examination results. The second sub-system concerns logistics and involves drug prescriptions. The third sub-system involves the daily administration information of the hospital, such as billing, receivables

3 https://www.ncbi.nlm.nih.gov/books/NBK233047/

management, inventory management, and staff salaries. Finally, the last sub-group concerns the clinical research module.

Seeing the importance of information technology for the strategic alignment of hospitals, governments have driven the adoption of EHRs. In the United States, there is at least an 80.5% adoption rate of EHRs by hospitals (Adler-Milstein et al., 2017). In France, after the initiation of the "hôpital numérique" program, more than 1,200 projects were launched between 2013 and 2018[4].

From this description, we can see that EHRs help hospital staff optimize patient management. On the other hand, PHRs target not the health organizations but rather individuals. Indeed, the term PHR is old, but the possibility of its application is very recent. The first appearance of this term came in 1969 to designate "a simple form of notes that contains information one needs in order to be informed about one's health, and early studies on PHRs focused on such paper records" (Kim et al., 2011). Later, with the standardization of health information, the term PHR began to be defined as health apps controlled by the patients themselves.

The recent popularity of PHRs is related to the paradigm shift to patient centeredness, meaning that patients have a more active role in their health (Kim et al., 2011).

An important trend in PHRs is the integration of PHRs with EMRs and EHRs so that hospitals can also easily access patient information (Detmer et al., 2008). In some case, the patient always remains the one who controls his or her information by voluntarily assigning access rights. But, in other cases, the patient has a read-only right through web portals provided by the healthcare facility.

Several contemporary companies have launched apps on the market. The results did not meet the expectations of these apps.

4https://solidarites-sante.gouv.fr/systeme-de-sante-et-medico-social/e-sante/sih/hopital-numerique/Hopital-Numerique

2. A review of the use of PHRs: Research versus practice

The objective of this section is to present the state of the literature and practice with respect to PHRs.

2.1 PHRs in the literature: A lot of knowledge but limited possibility for actions

To date, there are different definitions attributed to PHRs. Ideally, each individual should have a single PHR gathering all their medical information from various sources (laboratories, pharmacies, clinics, consultations, connected objects, insurance, etc.) (Roehrs et al., 2017). This type of PHR should be connected with the systems of the different health facilities.

The PHR can also be a web or mobile application that collects and stores patient data for one or more specific aspects of their health (Roehrs et al., 2017). This is the case for PHRs developed for self-monitoring of chronic diseases or apps available for monitoring physical activity and nutrition. This type of PHR can be standalone or connected with the systems of healthcare facilities.

Whatever the case, the objective is to improve the quality of care for patients by empowering them throughout the process. This is a shift from the traditional patient-physician relationship of leaving everything in the hands of the physician to a patient-centered medicine in which the individuals are responsible for making decisions and managing their own health (Kim et al., 2011). This shift has led to the emergence of several questions and studies relating to the empowerment and self-efficacy of individuals as primary elements for the adoption and use of PHRs. Other issues related to trust, privacy, and e-health literacy have emerged as potential barriers and obstacles to the judicious use of these PHRs (Tang et al., 2006; Vance et al., 2015).

In a more general way, research on PHRs increased around 2005 and is disseminated in the medical informatics and information systems management literature. These research works cover a variety of topics, such as design, description of the objectives, functionalities, challenges, the adoption, and use of PHRs (Kim et al., 2011). Several methodologies are used in these works, including surveys, interviews, focus groups, case studies, and experiments.

All these studies agree with the critical interest of PHR to improve patient safety through patient empowerment and the provision of information to support therapeutic decision making. However, the same issues are raised regarding low adoption and problems related to information quality and security (Norman Archer et al., 2011; Roehrs et al., 2017; Vance et al., 2015).

Each new study tries to provide a solution. Yet, the description that many authors make of this literature is that it is atheoretical and descriptive (Kim et al., 2011). Consequently, these studies don't have a significant impact on the field of PHRs, as we can see with the persistence of certain problems.

2.2 A few examples of PHRs: Failures and promises

Since the emergence of PHRs, digital giants such as Microsoft, Google, and Apple have put PHRs applications on the market. These applications have had a contradictory result to the expectations of the promoters, and several explanations have been given to this effect.

The first example we can mention is Google Health, launched in 2008. Unfortunately, this app was withdrawn from the market in 2012 because of the low adoption and the limited usage. Google actually wrote about it in 2011, saying, "We haven't found a way to translate that limited usage into widespread adoption in the daily health routines of millions of people."[5] In the aftermath, experts had a number of different theories for the failure. Some thought it was because consumers at the time weren't actually interested in taking direct control of their health records. Others said Google did not do enough to integrate with the health IT landscape or that the company didn't do enough to show people that it could be trusted with their health data. However, Google is re-entering this market with a second attempt at PHR, including modules for telemedicine and clinical research.[6]

5 https://googleblog.blogspot.com/2011/06/update-on-google-health-and-google.html

6 https://www.theverge.com/2021/4/12/22379846/google-health-record-data-app-android

Another example of a failed PHR is Microsoft being taken off the market in late 2019, the previously mentioned HealthVault that suffered from low adoption. The failure of this app was associated with the fact that it focused solely on traditional health data such as that found in EHRs instead of including mobile telemetry, health behavior data, or patient-acquired data that could be used for in-home health optimization. In addition, the lack of integration with existing systems has also hampered the spread of this app in the market.

A third example is that of Apple. Apple Health Records was launched in 2018 and includes lab results, medication information, etc. Individuals can save their health information on their Apple smartphones and merge them with other data acquired through self-monitoring in popular third-party apps and through wearables like glucose meters.

Through this diversity of attempts and projects to bring PHRs to market, we can see that supply is abundant while demand is still very low. Even if it is true that demand is growing in specific areas, such as chronic disease management or connected objects, in general, we are still at the beginning of the understanding of people's expectations and needs regarding PHRs.

2.3 From design to the adoption of PHR

The marketing of a PHR is preceded by many steps starting with the design. Adoption and use are indicators of market receptivity and is a condition the survival of the product. Moreover, these steps are interdependent.

Depending on the type of PHR and its target, the design and use could involve various stakeholders, such as individuals or patients, physicians, insurance, or policy makers (Mantzana et al., 2007; Payton et al., 2011).

The first challenge is to identify the needs of the target stakeholders in order to meet them through the PHR. It is at this level that many gaps may be found, because, despite all the studies on the perceptions of individuals, we are still in the early stages of identifying expectations regarding PHRs (Baudendistel et al., 2015). This complexity is linked to the diversity of objectives among stakeholders of different types and even among stakeholders of the same type (Gagnon et al., 2016). In addition, many elements must be considered to meet the needs of stakeholders in order to promote adoption and use. These elements are mainly

related to the factors that influence the adoption and use of the proposed PHRs (Baudendistel et al., 2015).

Among the main factors promoting or hindering the adoption and use of PHRs by stakeholders, we have the perceived benefits that take into account informational, emotional, and health benefits. Perceived benefits are the basis of technology adoption, as shown in adoption models such as the Technology Acceptance Model (TAM) (Davis et al., 1989; Venkatesh & Bala, 2008) and the Unified Theory for the Acceptance and Use of Technology (UTAUT) (Blut et al., 2021). Besides this, ease of use, which is often equated with usability, is also critical. Some studies show that it even influences the perception of usefulness or benefits (Venkatesh & Bala, 2008). This is also true with PHRs, so we have several laboratories, specialists, and researchers who focus on improving the usability of health applications. There are also factors such as e-health literacy, trust, or privacy. The latter is one of the main factors blocking the adoption of PHR. To overcome this, some have proposed technical and social measures--on the one hand to reinforce the technical architecture in order to limit the vulnerabilities in the system and, on the other hand, to make the actors aware of the need to adopt responsible behaviors in order not to create vulnerabilities (Spears & Barki, 2010). As far as physicians are concerned, their main fear with PHRs is related to the reliability of information, since the idea of PHRs is control by individuals. We have considered the case of individuals/patients and physicians only because they are the main ones concerned when it comes to PHRs. Very few studies include other stakeholders.

Apart from the various stakeholders that represent a reason for this complexity, we can also associate the various types of PHRs. Indeed, not all healthcare providers have the same weight in the care pathway of individuals. Some authors mention the fact that chronically ill people adopt health apps more easily because they use them on a daily basis to manage their health (N Archer et al., 2011; Cocosila & Archer, 2014; Jiang & Cameron, 2020; Laugesen & Hassanein, 2017). This type of individual is different from those who would simply be asked to use a health app for information purposes (Cocosila & Archer, 2014).

In the next section, we present the relevance and the interest of our focus on drug allergy information.

3. About the thesis

In this section, we present the thesis starting from its relevance, then the research questions, the research context, the methodological framework, and finally the structure of the thesis and the description of the doctoral work.

3.1 The relevance of the research

This research work is based on the evidence-based practice for information systems which advocates that research in information systems should be useful not only for other researchers but also for practitioners (Wainwright et al., 2018). This approach of doing research draws its foundation from evidence-based medicine (Sackett, 1997), which is really advanced to make the research knowledge available for practice. Concerning information systems research, we still have a long way to go.

Two paradigms characterize most information systems researches: (1) behavioral sciences and (2) design and action sciences (Hevner et al., 2004; Spagnoletti et al., 2015). The first category aims to describe, explain, analyze, and predict phenomena, whereas the second category aims to provide prescriptive knowledge through the design and evaluation of an artifact. These two approaches have often been the subject of the debate concerning rigor versus relevance (Baskerville et al., 2018). However, each of these research approaches is useful in advancing sciences and practice, and some points of complementarity have been found between them (Spagnoletti et al., 2015). This complementarity consists of the enrichment of the behavioral sciences by the outputs of design and action science studies, and, conversely, the design and action sciences should be nourished by theories from the behavioral sciences. Therefore, some authors call for more studies highlighting this complementarity (Mandviwalla, 2015). A simple case is the theories explaining technology adoption to build artifacts that consider the elements facilitating adoption by individuals and organizations (Hevner et al., 2004).

This project situates itself within this logic by highlighting the complementarity between the two paradigms. More concretely, we are interested in the design, evaluation, and adoption of a mobile health application in collaboration with a development company under an industrial Ph.D. contract.

3.2 Research context: Drug allergy information

Our research context is related to the tracing of drug allergy information. It is a unique case in this thesis because, as explained above, we could not include other cases due to external factors.

This case is related to a concrete project that we initiated with allergists of the university hospital of Montpellier to solve the problems they encounter in the daily process of drug allergy information. We collaborated in this project with the allergists of the University Hospital of Montpellier with a double objective, i.e., for research and for practice. The team was composed of three allergists, one of whom had started a thesis on the subject for the clinical part, in addition to my own, which was related to the functional needs, the design, and the evaluation of the application. Pikcio, the company in which I had an industrial thesis contract, was also part of the team.

The purpose of having an interdisciplinary team was to address the different aspects of the project, i.e., the technical aspect, the clinical aspect, and the intermediary between the two provided by my thesis directors and myself

Throughout this work, we often use the term allergy to refer to adverse reactions to highlight the fact that the two terms are often mistakenly confused (Ferner & McGettigan, 2020). Indeed, adverse drug reactions are undesirable effects that occur immediately or long after taking a drug. Depending on the situation, the individuals concerned should confer with their physician for the right decision to be made—i.e., to continue taking the medication or to stop it completely. In either case, accurate information about the type of reaction is necessary for the physician to make the appropriate decision.

In terms of statistics, only 10% of individuals who report a drug allergy are actually allergic (Pawankar et al., 2013). And, on the other hand, uninformed drug allergy information is the cause of 12% of medical errors (Barton et al., 2012).

We can thus draw important information about drug allergies:

- The existence of an allergy to a drug molecule is an eliminatory criterion for individuals.

- Reactions that occur after taking a drug can be allergies or adverse reactions not of concern.

- Some reactions are acceptable when they are not serious and do not involve the non-recommendation of the drug molecule.

- Information about an individual's drug allergies is vital for making the right decision and ensuring the safety of this individual.

Therefore, professionals and health administrations have proposed many types of paper documents to collect and track information on drug allergies. But, with the trend of digitization of healthcare, several authors have proposed the use of information technology for collecting, storing, and sharing drug allergy information. In addition to EMRs, some health apps on smartphones incorporate the ability to record allergies.

These different solutions, however, have many limitations in terms of completeness, availability, accuracy, traceability, and accessibility of information.

3.3 Research questions

It is astonishing to note that, despite all the studies and projects related to PHRs, the same problems persist. Among these problems, we can mention unclear users need, the information quality, and adoption (Lester et al., 2016). Many have attempted to explain these issues, and there are even several proposed solutions, but the applicability in a concrete project is still very limited.

Subsequently, we have very general knowledge that does not take into account the peculiarities of concrete cases, which makes this knowledge difficult to use. It is in this sense that Wainwright et Al. (2018) deplore the fact that information systems researchers do research for other researchers.

It is therefore very difficult at this time to come up with a clear guide of best practices tested on design to the adoption of a PHR.

Starting from a given field problem related to drug allergy information, especially when the need for a health application arose, we asked ourselves the following: **What are the ideal**

characteristics of a PHR that would be accepted by individuals and that would meet their need for successful adoption and use? What are the elements that should be considered? Would it be possible to create such an application in a scientific manner by bringing out rigorous actionable knowledge? Our objective was to attempt to build and evaluate such a PHR using design sciences.

This general questioning has been broken down into several research sub-questions that we have addressed in each of our papers below (see Table 1).

Table 1. Research questions by paper

Paper	Objective	Research questions
Paper 1	Use the blockchain technology to answer user needs related to PHR.	RQ1: How to build an effective blockchain-based health solution that deals with real-life issues?
Paper 2	Provide actionable knowledge for practitioners to address adoption issues.	RQ2: What are the perceptions of users about the adoption of the digital allergy card, and how can they be used to facilitate adoption issues?
Paper 3	Provide actionable knowledge to address information quality issues with e-health application.	RQ3: How can we concretely prevent information quality issues while designing e-health applications?
Paper 4	Analyze the impact of the context on the intention to use personal health records.	RQ4: How does the situational trade-off of benefits and risks affect the adoption of a PHR?

The first paper focuses on using blockchain to improve the existing situation regarding drug allergy information. The goal is twofold because, in this paper, we also wanted to explore the feasibility of blockchain in healthcare given all the promises of researchers and practitioners on this subject (RQ1). The second paper deals with the issue of adoption by trying to extract from users' perceptions actionable elements to be put in place during the design of the application (RQ2). The third paper follows almost the same logic as the previous one, but this

time we address information quality with the objective of taking action from the application features to prevent information quality problems (RQ3). Finally, the fourth paper returns to the question of adoption but this time with an experimental study to test some elements that emerged during the reflection on paper 2. The idea is to validate these elements so that the knowledge is more solid, rigorous, and even generalizable (RQ4).

3.4 Methodological framework: The design impacts the adoption

Our research work is mainly based on action design research, which is an interventionist methodology of Design Sciences Research (DSR). Indeed, it is a combination of design sciences and action research (Sein et al., 2011).

This methodological approach is in line with our critical realist epistemological position in the sense that the objective of our study is "to discover mechanisms and structures in order to allow their modification" (Fortin-Dufour, 2013). Indeed, the critical realist stream maintains that the reality exists independently of whether it is observed or not (Strong & Volkoff, 2010; Volkoff & Strong, 2013). Therefore, theories are not fixed since they evolve according to what is observed in the empirical domain. So, the role of researcher is to discover the reality and make necessary changes on it.

DSR is a research stream whose goal is to create knowledge through the design of innovative artifacts (Baskerville et al., 2018). As mentioned above, the discipline of information systems contains two paradigms that complement each other. The design sciences involve all decisions made for the system development methodology used and the functional capabilities, information contents, and human interfaces implemented within the information system (Hevner et al., 2004). These decisions are crucial in information systems because they impact and are impacted by the behavior and interactions of the different actors. The methodologies of design sciences do not necessarily imply the intervention of the researcher in the creation of the artifact.

Action research is an interventionist method that allows the researcher to be an actor in the research field. Action research briefly consists in better defining a problem in an environment involving the researcher with the objective of improving the situation observed (Burns, 2009;

Lindgren et al., 2004). It contrasts with other methods that do not necessarily involve an immediate change in the situation.

When action research is intertwined with design science, it forms action design research (ADR) with the objective to build an artifact and evaluating it by collecting data throughout the process to improve the artifact in an iterative way (Sein et al., 2011). ADR aims to solve concrete problems in the field by proposing useful and actionable knowledge for researchers (Gregor & Hevner, 2013). This is why ADR corresponds to research problems that start from a field problem, as is the case in our thesis. Another reason for using this methodological framework is the intervention of the researcher, which is a strong characteristic of our work since we have been involved throughout the needs analysis, the design, and the evaluation of the application.

ADR is based on several fundamental principles:

i) Practice-inspired research,

ii) Theory-ingrained artifact,

iii) Reciprocal shaping,

iv) Mutually influential roles,

v) Authentic and concurrent evaluation,

vi) Guided emergence, and

vii) Generalized outcomes.

Based on these principles, we have worked on the design and evaluation of a digital allergy card that is an application for patients and physicians. We followed the proceeding steps: problem formulation to clarify the need; building, intervention, and evaluation to iteratively think, implement, and evaluate the solution; reflection and learning; and formalization of the learning (Mettler, 2018; Sein et al., 2011).

Later, we used the outputs of the design research to enrich a model for an experimental study to explain the adoption of the application we discuss. This last step of our methodological

framework aligns with the logic of our research, which aims to highlight the complementarity between the behavioral sciences and the design and action sciences. This step of our work is also important because it would allow us to test and validate the knowledge coming out of the design process and thus to promote generalizability, which is still a problem and a weakness of design science work.

Table 2. Synthesis of the methodologies by papers

<table>
<tr><th></th><th>Method</th><th>Data collection</th><th>Data analysis</th></tr>
<tr><td>Paper 1</td><td rowspan="3">Action design research</td><td rowspan="3">Participation in team meetings, dozen of email discussions about the problem formulation,

interviews with patients and physician during the evaluation round of the application</td><td>Content analysis</td></tr>
<tr><td>Paper 2</td><td>Thematic analysis inspired by the grounded theory (Corbin & Strauss, 1990).</td></tr>
<tr><td>Paper 3</td><td>Thematic analysis inspired by the method of Gioa et Al. (2013). We used the information quality dimensions as our framework.</td></tr>
<tr><td>Paper 4</td><td>Experimental with the scenario method to test a two-factor model</td><td>In progress

Data collection in the allergology unit of the University Hospital of Montpellier</td><td></td></tr>
</table>

3.5 Theoretical framework

To answer our different research questions, we have mobilized different theoretical frameworks in our papers.

Paper 1 and paper 2 have a grounding logic, so they do not imply a theoretical framework and are just based on the literature related to PHRs and the question addressed. In paper 3 and paper 4, we integrate two theoretical frameworks.

3.5.1 The affordances perspective to provide actionable knowledge

In order to implement the elements to prevent information during the design of the DAC, we mobilize the affordances framework.

The concept of affordance, originally described in ecological psychology by Gibson (1979), is the subject of a recent resurgence of interest in the information systems literature for the study of the use of IT artifacts in organizations (Majchrzak & Markus, 2012; Markus & Silver, 2008) and the resulting organizational changes (Leonardi, 2013; Volkoff & Strong, 2013). For Gibson, affordance refers to "what is offered or provided for someone by an object," i.e., the possibility offered to a human being (or animal) to use an element of the environment toward a goal (Gibson, 1979). According to the information that the human being has on what he can do with this element, he perceives the affordance or not: "The question is not whether affordances exist, but whether information is available for perceiving them."

A transposition of this definition of affordances has been proposed by Norman. He emphasizes the relational dimension and defines affordances as human-machine interactions that must be taken into account during the design of application (Norman, 1999). Indeed, he argues that the goal of design is to make affordances—that is, what a user can do with the technology—easily perceivable by users (Norman, 1999). Subsequently, several approaches have been developed in the IS literature (Pozzi et al., 2014b), with different focuses centered on the very existence of affordances, their perceptions, their actualizations, their effects, or even the transformations of the organization induced by affordances not anticipated in the design (Leonardi, 2013; Volkoff & Strong, 2013).

More particularly concerning the problems of our paper, which is about information quality, the affordances perspective offers the best way to implement the necessary features to make the human-machine interactions with the application fit with the information quality requirements. This is because affordances have been evaluated as antecedents of information quality (Grgecic et al., 2015). In other words, information quality is the result of the interaction between the user and the system made possible by the affordances.

The affordances perspective is all the more interesting since it integrates the actionable side, which is crucial to guide actions in the field. This aspect corresponds to our research logic based on evidence-based practice for information systems.

3.5.2. The situational privacy calculus perspective for the adoption of PHR

The calculus behavior is inherent in the adoption of information technology, as shown in the work of Venkatesh when he states that, despite the impact that perceived ease of use has on adoption, it is less important when the perceived usefulness of the application is salient for the user (Venkatesh & Bala, 2008). Calculus behavior is the attitude of individuals to weigh the pros and cons before making a decision.

Privacy issues are considered a negative determinant of intention to use because the more important they are the less likely the individual is to adopt the application or service (Dinev et al., 2013; Featherman et al., 2010; Li et al., 2010). In healthcare, privacy is even more important due to the sensitivity of the information. Yet, its impact on intention to use may be overshadowed by the benefits of using the application. Concurrently, however, its impact on the intention to use may be masked by the benefits of using this application, especially when the stimulus of the current situation experienced by the individual accentuates these benefits (Li et al., 2010).

It is in this sense that several authors have shown that, in the context of e-commerce, information security, or marketing, the stimulus of the individual's situation can positively impact adoption behavior (Beke et al., 2021). An example cited in the literature is that of a weather application that offers personalized services to individuals; in this study, the author shows that, in emergency situations, the intention to use would be positively affected (Sheng et al., 2008).

We use this perspective in our study to explain DAC adoption in different contexts. More specifically, the aim is to see how adoption behavior varies in different situations, either by accentuating benefits and mitigating privacy concerns or the opposite.

4. Structure of the thesis and the organization of the doctoral work

This thesis is in the format of an essay thesis in which we will present four papers.

Table 3. Overview of the four papers

	Title	Status	Authors
Paper 1 (Chapter)	A use case of blockchain in healthcare: Digital allergy card	Published by *Springer* in 2020	Rhode Ghislaine Nguewo Ngassam, Roxana Ologeanu-Taddei, Jorick Lartigau, Isabelle Bourdon
Paper 2 (Review Paper)	An action design research to facilitate the adoption of personal health records: The case of digital allergy card	Accepted for publication in the *Journal of Organizational and End User Computing*	Rhode Ghislaine Nguewo Ngassam, Linnea Ung Roxana Ologeanu-Taddei, Jorick Lartigau, Pascal Demoly, Isabelle Bourdon, Nicolas Molinari, Anca Mirela Chiriac
Paper 3 (Review paper)	Affordances-based approach to health application design to improve the quality of health information: The case of a digital allergy card	In progress after a rejection at *BISE* New target: *Communication for the Association of Information Systems (CAIS)*	Rhode Ghislaine Nguewo Ngassam, Roxana Ologeanu-Taddei, Isabelle Bourdon

Paper 4 (Review paper)	Does the privacy really matter for the adoption of a Personal Health Record: A field experiment design	Work in progress We target a rank 2 or 3 review	Rhode Ghislaine Nguewo Ngassam, Roxana Ologeanu-Taddei, Isabelle Bourdon, Thao Bui Nguyen

Paper 1 presents the design process of a blockchain-based digital allergy card. In it, we highlight the field needs that the specifics of blockchain could address. To do so, we use a 10-step decision model. This paper has highlighted the information quality needs that we sort out in more detail in paper 3 using the affordances perspective to propose actionable knowledge unlike existing information quality studies that are more descriptive, analytical, and explanatory.

Paper 2 focuses on the issue of adoption, based on the fact that the literature is limited when it comes to applying existing knowledge to concrete cases. Based on the findings of this paper, we develop Paper 4, which is an experimental study to test the results obtained in Paper 2.

This doctoral work was conducted over three years on a full-time basis. At the beginning, it was a contract with a company with the objective to explore the use cases of blockchain in health. Afterwards, funding concerns led to the closure of the company and thus the suspension of all ongoing projects.

In my first year of my PhD, I was involved in the research of cases in health where we could apply blockchain. We had several leads, including patient and doctor identification in the hospital, insurance reimbursements in self-medication, tracking consents, and tracking drug allergy information. Only the last project made progress between the start of the thesis and the closing of the company. For the tracing of patient consents, we were able to carry out the analysis of the existing system by a short stay in the partner health establishment of the project. Far from being completely abandoned, my interest for this subject remains and is part of my research agenda after this thesis. For the other two projects, we did not advance further than the conceptualization stage with the partner companies.

The main source of data was therefore the University Hospital of Montpellier, in particular the allergology unit where we conducted design meetings and evaluation interviews of the

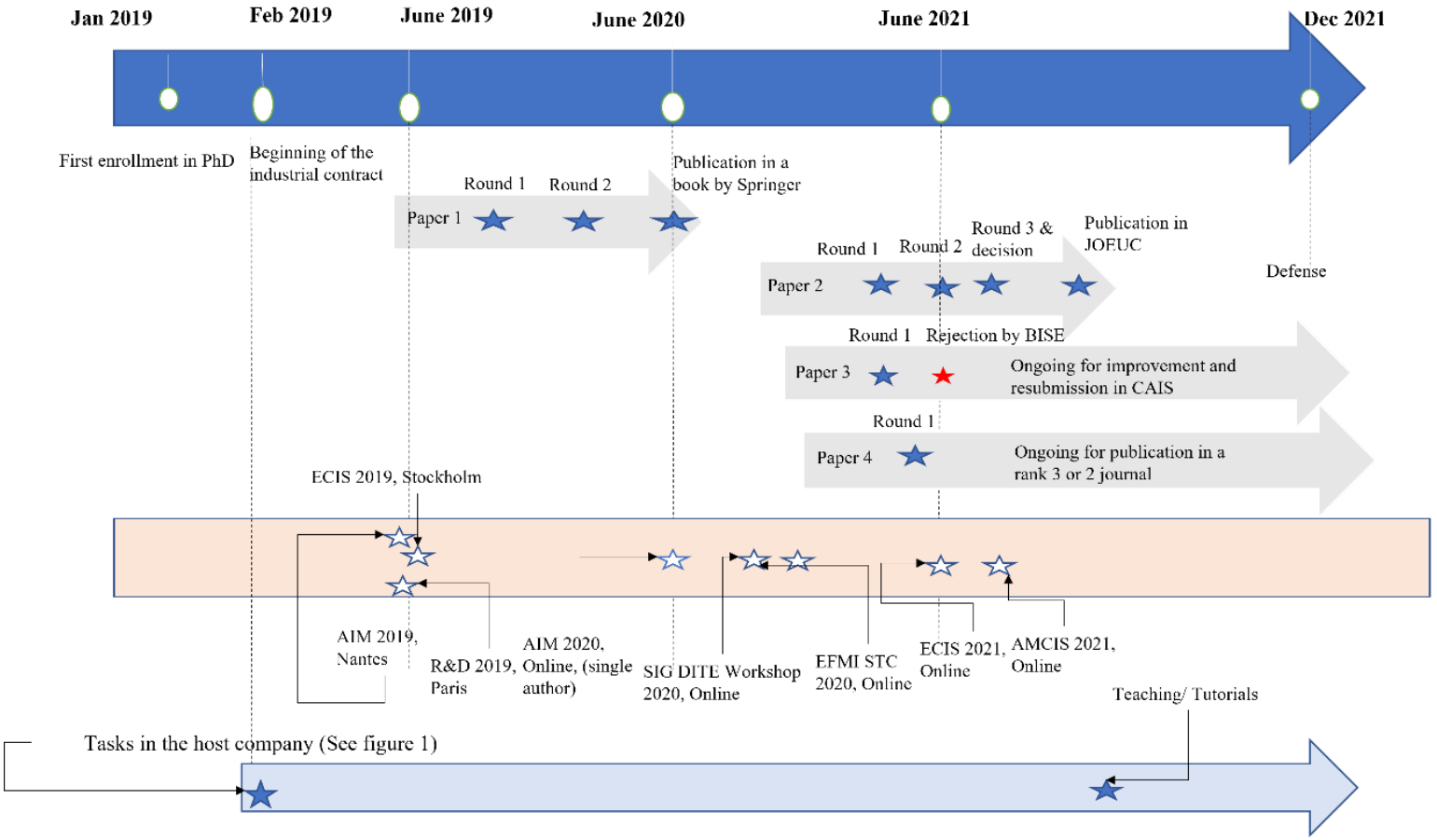
digital allergy card prototype. This is the same source we used for our experimental study on the adoption of the digital allergy card..

My work time was divided at the beginning of the thesis as follows: 60% for the company and 40% in the laboratory. This organization was later changed in favor of the time allocated to the lab at the university (i.e., 30% for the company and 70% in the lab).

The back and forth between the company and the actual research work allowed me to participate in eight conferences, including a workshop, two doctoral consortia, and six communications. Outside the framework of the conferences, I also participated in one scientific workshop for writing journal papers with a Special Interest Group (SIG) of the Association for Information Systems (AIS).

The next chapters present the four papers of the thesis. Then we will have the chapter on the general discussion and another on the general conclusion. Finally, we will present the appendices and the bibliography.

Figure 3. Organization of the doctoral work



PAPERS OF THE THESIS

PAPER 1

“A use case of blockchain in healthcare: digital allergy card”

1. Information about the paper

This paper is the result of the field experience during the first months of my thesis. When we began the first use case concerning the tracking of drug allergy information, we started the project with the needs analysis and the exploration of the feasibility of blockchain. Subsequently, we proposed a paper at the R&D 2019 conference, which we attended from June 19–21, 2019.

We also proposed an abstract for an ECIS 2019 workshop whose theme was blockchain. Following this workshop, we wrote this book chapter describing the different steps of our reflection on the feasibility and integration of a private blockchain in the case of a digital allergy card.

Title	A use case of blockchain in healthcare: digital allergy card
Status	Chapter published in 2020
Access	https://link.springer.com/chapter/10.1007/978-3-030-44337-5_4
Reference	Ngassam, R. G. N., Ologeanu-Taddei, R., Lartigau, J., & Bourdon, I. (2020). A use case of blockchain in Healthcare: allergy card. In Blockchain and Distributed Ledger Technology Use Cases (pp. 69-94). Springer, Cham.
Authors	Rhode Ghislaine Nguewo Ngassam; Roxana Ologeanu-Taddei, Jorick Lartigau, Isabelle Bourdon
Related communication	European Conference for Information System (ECIS) 2019 workshop on the blockchain: “The fit construction process between a blockchain system and a use case in healthcare” presented at Stockholm in June 2019 Conference R&D 2019: “Digital service innovation enabled by the

	blockchain use in healthcare: the case of the allergic patients ledger" presented at Polytech Paris in June 2019
Abstract	Blockchain has often been mentioned in recent years as being a promising innovation for the healthcare sector in that it can ensure the secure exchange and traceability of information while respecting the regulatory framework for the confidentiality and portability of healthcare data. However, concrete cases remain very rare in the literature, and we investigate relevant use cases applying blockchain in healthcare. This chapter shows how we design a blockchain-based allergy card to solve real-life issues that is register, share and trace information about drug allergies. Therefore, we iteratively use action design research to determine the needs, design solution, develop the application and evaluate outcomes by involving stakeholders in the construction and evaluation.
Key words	private blockchain, allergy card, traceability, security, healthcare

2. Published text

2.1 Introduction

In recent years, health information systems have faced several challenges in terms of accessibility (Omary et al., 2011) privacy and traceability (Cruz-Correia et al., 2013) of medical information. Indeed, these elements are decisive in the care of patient because they allow to ensure the continuity of care based on reliable information. This situation is obvious for drug allergies information whose difficult access and inaccuracy are very harmful for patients' care (Demoly et al., 2014). As a result, the community of researchers and practitioners in information systems are developing a greater interest in the design and implementation of digital tools aimed at optimizing the patient's care pathway and facilitating the work of healthcare professionals (Blumenthal & Tavenner, 2010). Since, several medical software and applications projects have emerged. However, these solutions have revealed weaknesses in terms of adoption (Sligo et al., 2017), regulatory compliance and interoperability with existing systems (Omary et al., 2011).

Meanwhile, blockchain technology, after being applied to finance, has begun to attract the interest of researchers and practitioners from other sectors, including the healthcare sector, since 2015 (Hölbl et al., 2018). Therefore, many papers from academia and companies have been published to describe the potentialities of blockchain in healthcare as well as present some use cases tending to demonstrate that blockchain technology is a boon for all these technological challenges faced by the healthcare sector. The number of these papers has evolved rapidly, and we can cluster the content of all these papers into three groups: technical, reports, and applications (Agbo et al., 2019).

However, the ever-growing number of studies on the use of this technology in health contrasts with the number of studies related to successful implementation and evaluation of blockchain-based health solutions to meet the real needs of users (Agbo et al., 2019) because all these studies are mainly descriptive either of possible opportunities or of some developed tool (Hölbl et al., 2018). Evidence suggests that current blockchain studies in healthcare sector focus more on technological aspect than on other; while several other aspects such human factors must be also considered, for the solution to be successful (Sligo et al., 2017). Indeed, numerous studies have shown that human factors are mainly related to the utility (need-

centric i.e. solve real-life problem) and ease of use (usability). To fill this gap, our study aims to answer the question:

How to build an effective blockchain-based health solution that deals with real-life issues?

The main objective of this chapter is to describe the building process of a blockchain-based allergy card to solve problems identified by allergists. To meet this objective, we use an action design research methodology to combine theoretical development, application through use cases and evaluation for improvement. The reminder of this chapter presents a background on blockchain in healthcare, the problem and relevance, the methodology, results, implications as well as conclusion and future directions.

2.2Background of blockchain in healthcare

When blockchain is discussed in regard to the healthcare sector, several usages are prioritized, including electronic healthcare records, drug / pharmaceutical supply chain management, remote patient monitoring, biomedical / clinical research and insurance claims, among others (Agbo et al., 2019). Some authors go even further and describe in detail what can be done with this technology. In this sense, Rabah (2017) presents a list of opportunities for the application of blockchain in the healthcare sector:

- Drug traceability. Each transaction between drug manufacturers, wholesalers, pharmacists and patients can be tracked to verify and secure drug product information that is important for tackling issues such as counterfeit drugs,
- Improvement and authentication of healthcare records and protocols for record sharing,
- Detecting drugs that, by error, do not contain the intended active ingredients they are meant to and can lead to patient harm,
- Smart contracts in which certain rule-based methods are created for patient data access. Here, permissions can be granted to selected healthcare organizations,
- Clinical trials in which fraudulently altering or modifying data from clinical trials can be eradicated,
- Precision medicine through which patients, researchers and healthcare providers can collaborate to develop individualized care,

- Genomics research via access to genetic data secured on blockchain.
- Electronic health records,
- Nationwide interoperability,
- Recall management. One million people are killed each year worldwide from counterfeit drugs. Better tracking through the supply chain has a significant effect at the human level,
- Prescription drug abuse, which is often made possible by disconnected healthcare records across hospitals, walk-in clinics, physicians and pharmacies.

Through these use cases, the benefits of blockchain applied in healthcare can easily be deduced and presented in the following Table 4.

Table 4. Key benefits of blockchain in healthcare (Kuo et al., 2017)

Key benefits	**Description**
Decentralized Management	Patients can manage these healthcare records themselves; we can have real time processes, and data sharing is improved
Immutable Audit Trail	Data stored in the chain are immutable, enabling the detection of fraud or simply the accountability of all the users
Data Provenance	The signature embedded in each information makes it possible to trace the source of this information
Robustness/Availability	Data are not held by a single institution but can be shared among several organizations
Security/Privacy	The encryption of data that can be decrypted only with a patient key increases the

	security of healthcare data

However, while this technology seems to have several applications in the healthcare sector to make data secure, traceable and portable, the Table 5 presents some challenges and the solutions found in the literature.

Table 5. Challenges of blockchain

Challenges	**Proposed solution in the literature**	**References**
Anonymity	Patients grant access to identified persons or institutions	(Hölbl et al., 2018)
Security / privacy	Access control, right granted by patients	(Hölbl et al., 2018)
Scalability and data management	Data are not stored in the chain but in a data lake (a data repository enabling the storage of diverse data types)	(Linn & Koo, 2016)

In short, the literature is only a reflection of the growing interest in applying blockchain to healthcare. Paradoxically, it lacks concrete elements to prove the real need of blockchain for the applications that are mentioned. Similarly, there is a lack of studies demonstrating implementations in a functional environment (Hölbl et al., 2018). The purpose of this chapter is to demonstrate how we have evolved from an existing need with regard to drug allergies to a blockchain-based solution. Therefore, we will show how current processes related to drug allergy information sharing will be impacted and how users will be involved to ensure the relevance of the application.

2.2.1 Problem and relevance

Drug Hypersensitivity Reactions (DHRs) suspicions affect more than 7% of the general population (Demoly et al., 2014). DHRs can be life-threatening, even fatal, and may require a prolonged hospitalization, with changes in therapy. Thus, they represent an important public health problem (Demoly et al., 2014; Gomes et al., 2004). Globally, depending on the clinical history and the culprit drug, about 1 in 5 patients is confirmed to be allergic following allergy testing (Brockow et al., 2016). Therefore, in most situations, the label of drug allergy determines the therapeutic choices of the patient (Jones & Como, 2003). Drug allergy is believed to be lifelong in many patients. Thus, a formal allergy work-up should be ideally performed, in order to confirm or rule out the diagnosis. Indeed, underdiagnosis (under-reporting) and overdiagnosis (suspicion of allergy, based only on the clinical history alone for example) lead to misdiagnosis which may affect future therapeutic options and lead to the use of more-expensive and potentially less-effective drugs (Golden et al., 2011). If the drug allergy is confirmed, the culprit drug (and potentially cross-reactive drugs) must be avoided. Re-administration of a drug the patient is allergic to is the most important risk factor for the recurrence of more severe and life-threatening reactions (Apter et al., 2004). However, this avoidance is not achieved in all patients (Jones & Como, 2003), accidentally or intentionally. Most "errors" of prescription result from:

- Ignorance of a patient's allergy,
- Poor documentation (Villamañán et al., 2011),
- Lack of knowledge: the treating physician may not be aware that the prescribed drug is potentially cross-reactive or does not think that the allergy is real. The lack of knowledge may be caused by (Khalil et al., 2011): (i) failure to collect relevant information from patients, (ii) patients failing to report their allergy to physicians, (iii) patients forgetting their allergy, (iv) inability to recognize the allergy. The latter has been found to cause approximately 12.1% of medication errors that usually result in adverse drug events (Lesar et al., 1997),
- The re-administration was chosen despite the acknowledgement of the allergy and after assessing the risk/benefit balance.

On the other hand, it has been proven that even with clear drug allergy delabeling practices, up to one third of patients (or their prescribing physician) continue to erroneously report a

drug allergy, rendering the de-labeling process less effective. Patients and their care providers need adequate communication and education at the time of any change in allergy status, including clear documentation guidance. Actually, a drug allergy can be communicated orally or based on a written document which should ideally be universal (Khalil et al., 2011). Indeed, such a document should be available for domestic but also international use and fulfill several criteria: intuitive, readable, understandable abroad and with generic name of the drug. The main purposes of an allergy document are mainly related to the safety of patients by informing them as well as their physicians, the possibility for physicians to treat with possible alternative medication, the provision of expert information on reliability and the high lightening of previous life-threatening reactions. In 2016, a task force by the European Network of Drug Allergy/EAACI Drug Allergy Interest Group (Brockow et al., 2016) has analyzed the documentation provided by allergy centers in Europe (see Figure 1).

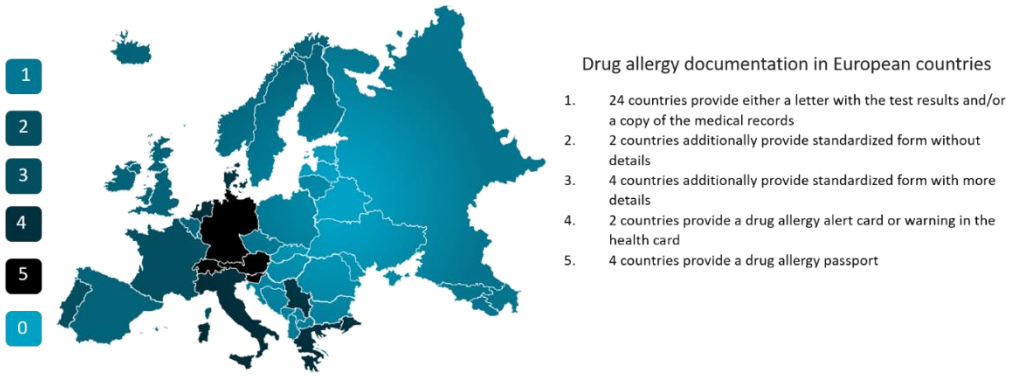


Figure 4. Map of allergy documentation in Europe (Adapted from (Brockow et al., 2016))

This task force emphasized the fact that allergy documentation was not standardized, and that the information could be provided under different forms (allergy card, allergy passport, medical letter, with or without details). A documentation was issued and selected by the members of the expert group as a usable drug allergy pass.

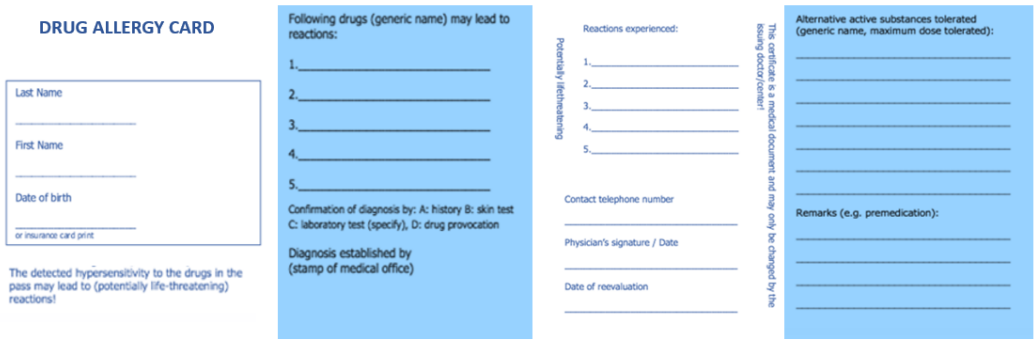


Figure 5. Paper documentation of Drug Allergy (Adapted from (Brockow et al., 2016))

Figure 5 presents the selected paper-based documentation that carries information on patient identity, risky drugs, alternative drugs tolerated by the patient, details on reactions as well as the signature and stamp of the physician. Actually, this document is mainly used after the allergic investigation has been performed, whereas the information on potential drug allergies (and their grading as "confirmed", "ruled out", "possible or probable") is also needed beforehand. Usually, before meeting the allergist, the patients themselves will write a note or will give orally the information to their care providers or will obtain a letter mentioning the occurrence of the alleged allergic reaction. Paper documentation can be forgotten or lost, therefore leading to loss of information. Also, the multitude of information needed but not always essential cannot all appear on a paper documentation and having it available in electronic form is the solution. The existing solutions have the following weaknesses:

- Paper-based solutions are not are not sufficient to contain all important information on drug allergy,
- The risk of information loss is very high since an oral information can be forgotten and a paper-based solution such as an allergy card or letter can be easily lost,
- Information is not unified because the documentation depends on the healthcare professional in charge of the patient,
- Information is not easily exploitable outside the health facility that created it because patient records are not interoperable.

We rely on the need for a digital card to report and share allergy data after several meetings and working sessions with a team of allergists who had identified the problem described above. Indeed, with the development of information technology-based approaches, a Digital

Allergy Documentation (DAD) could be the appropriate standardized tool involving all the data, in a suitable language. The field of mobile application grows fast, with the development of healthcare related Apps and devices whose main purpose is to improve patient care. A DAD would have several advantages compared to paper documentation:

- It can be filled by different users (patients, physicians, nurses, any care providers),
- All the information (whether literal or photos which are essential in drug allergy diagnosis) can be registered and uploaded,
- The information is available anytime, in case of emergency,
- The information can be standardized,
- The contents can follow the recommendations of allergist' groups.

Table 6. Comparison between a DAD and a paper documentation

Elements	Digital allergic documentation	Paper documentation
Medical content	Exhaustive memory, chronologic structure of the allergy follow-up	Instantaneous information because the physician should look for the information of a specific patient with a digital tool instead of only look directly at the paper presented by the patient
	Possibility to include a validation scale (tested and confirmed /ruled out/ not tested/ possible / probable)	Limited information (due to the limited size of the document)
	Possibility to provide data on alternative medication	
	Possibility to share specific	

	medical advice (e.g., list of medications to avoid) and guidance	
Quality of the medical content	Same information, shared according to a clear chronology, available for multiple end-readers	lack of information, available (or not) according to their addition on the paper support
Availability	Anytime, anywhere, possibility to avoid data loss with backups	Only if carried by the patient, if the paper is lost, the information is lost as well.
Course of the disease	Any additional information is structured chronologically and can capture the flow history of the allergy follow-up	Adding non-structured information is possible

2.3Methodology

Our project focuses on the construction of a blockchain-based mobile application for the reporting and sharing of allergy information between patients and their various healthcare professionals. The main purpose of this project is to use blockchain technology in a problem-driven user-centric approach. Therefore, we use the methodology of action design research to design an application that truly fits the needs of the final users. Action design research is a method that combines design science research and the interventions that the researcher or research team propose for the project as action research (Sein et al., 2011). In the case of our project, there is a multidisciplinary team composed of allergists who contribute to the clinical part of the tool, the company Pikcio, which develops a blockchain technology, and a university research team focusing on the information system for needs analysis and solution modeling. According to the action design research (ADR) principles, our project follows a

three-step (Figure 6) methodology before formalizing the outcomes as a mobile application for the reporting and sharing of information about patients' drug allergies (Sein et al., 2011).

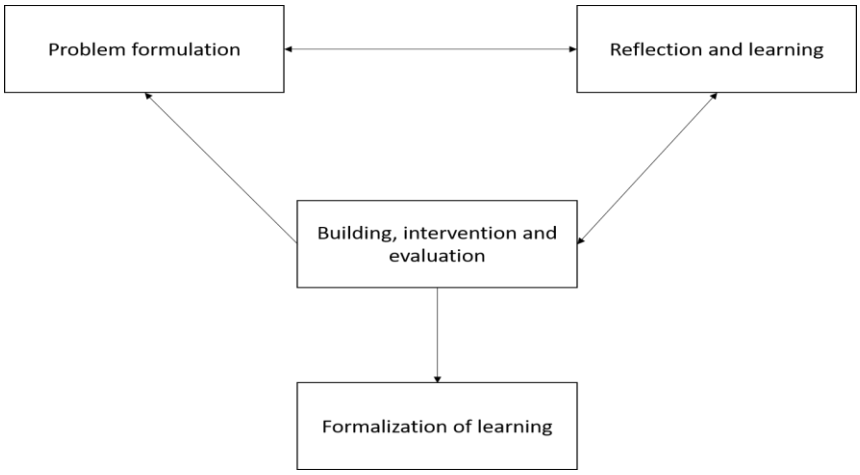


Figure 6. Action design research (adapted from (Sein et al., 2011))

Summarized in Figure 6, this method shows how we iteratively refine the formulation of the problem or need, the proposed intervention, the evaluation, and the learning and its formalization.

2.3.1 Problem formulation

In this stage , during many meetings, allergists describe the current operation of healthcare processes with regard to allergies, especially in France and we analyze this process to identify problems. Indeed, when an adverse drug reaction occurs, the patient can either keep the information to communicate it orally during his or her next care episode or directly report it to a physician. The physician can either directly consider the information as given by the patient or examine him or her to ensure consistency and the possibility of an allergy. The physician can then either record the information in the patient's file, draw up an allergy card or recommend the patient to an allergist for extensive testing. Note, the allergist can be directly contacted by the patient him or herself to schedule allergy testing. The allergist can either report the test results in the patient's file or establish an allergy card. Regardless of the situation, the information on the allergy, when it exists, must be communicated to prevent the administration of risky drugs to the patient (Brockow et al., 2016). The riskiest part of this

process is the management of a patient when he or she is unconscious by a physician who does not hold information about his or her allergy history.

2.3.2 Reflection and learning

The second stage allows us to think about different strategies and actions to address the identified problems and, in some cases, return to the previous step. Several authors have built a decision-making process around whether to use the blockchain (Pedersen et al., 2019; Wüst & Gervais, 2018). Based on the model proposed by Pedersen, Risius and Beck (2019) in Figure 7, we design a decision process for the use of blockchain, and the type of blockchain to use. We have further matched this process with our project related to the use of blockchain technology to ensure the decentralized management of allergy information, the availability of the data and the secure exchange of this information.

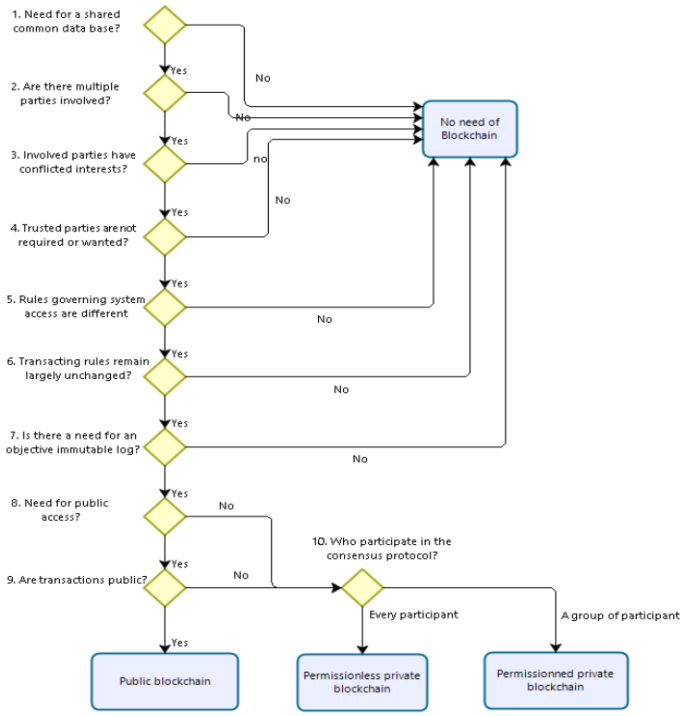


Figure 7. A ten-step decision path for the choice of blockchain (Adapted from (Pedersen et al., 2019))

Each number in this figure representing a step in the decision process, we explain them successively below by drawing a parallel with our case.

(1) As we have many actors who are potential sources of information, there is a need for a common decentralized database to make it possible to save the entire audit trail of information, regardless of who is the author,

(2) The parties affected by the information on allergies are patients; healthcare professionals, such as general physicians, specialists, pharmacists; and clinical research organizations,

(3) Patients tend to abuse the term allergy by claiming to have an allergy following any adverse drug reaction. Similarly, physicians are divided between the obligation to take into account the information given by the patient (which is often not validated) and their forensic responsibility in case of medical errors. In this way, it can be said that while for patients the verifiability of the information is not of great importance, for physicians, it is very important, as their care strategy is strongly impacted,

(4) There is no need for a trusted third party to manage this information because currently, there is no organization responsible for the validation of allergies. The only validators are physicians themselves who report the validated information in a paper document for the patient and/or in the internal file of the patient in the hospital. The aim is therefore to strengthen this existing data exchange structure that is made from physician to patient and vice versa. Moreover, international allergy organizations recommend to build patient-centric tools with patient empowerment over their health information,

(5) The information coming from the patient has the value of only declared information, yet the physician has additional functionality allowing him to validate the information. Access levels are therefore different depending on the profile of the user,

(6) Transaction stability is ensured because the registration, validation, and sharing of information about allergies are fairly defined processes,

(7) The need to access information and chronologically organize allergy information and the importance of the source of information make an immutable log indispensable.

(8) (9) and (10) are related to blockchain permission levels (e.g. private or public). The sensitivity of healthcare information makes it necessary to use a permissioned blockchain with interorganizational consensus.

After concluding the need for blockchain technology in our project, we analyze the private blockchain that underlies our application. Indeed, we use a permissioned blockchain named PikcioChain in this project whose structure is displayed in Figure 8 below.

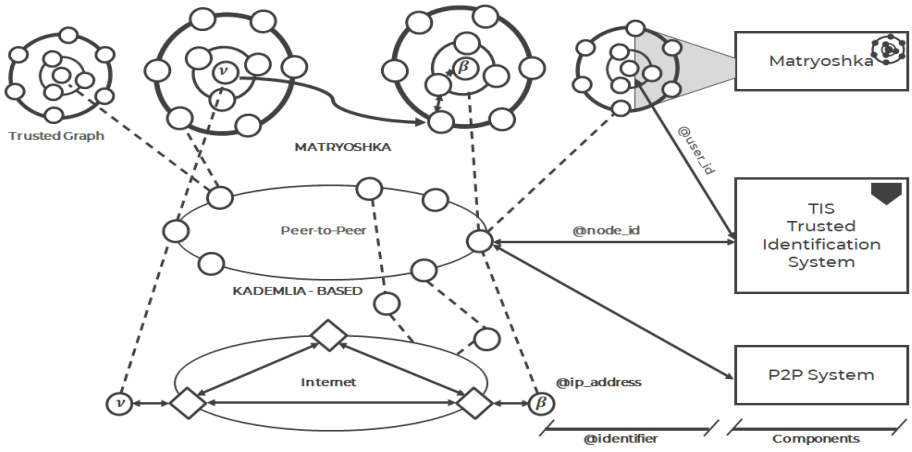


Figure 8. PikcioChain main components

PikcioChain achieves privacy by design in that it has been designed as a network addressing privacy from the very beginning (Lartigau et al., 2018). Privacy from centralized omniscient entities is achieved with the adoption of a decentralized P2P (peer to peer) approach. Privacy from malicious users is achieved with communication obfuscation through anonymous routing techniques such as matryoshka, data confidentiality through the use of encryption, and profile integrity through certified identifiers.

Indeed, most P2P networks suffer from a privacy problem that is due to the scheme itself. Since all the services interplaying among participants are executed in direct lines, tracing communications by very simple means would disclose the communication relationships in the network. When a blockchain is permissioned, for example, because of the legal requirements or the sensitivity of data, the addresses of miners and ledger hosts represent sensitive information, especially regarding network attacks. The adoption of anonymous communication techniques seems to be an obvious step towards the security objective of protecting trust links from community members. However, such anonymous communication techniques should be in line with the design principle of trust. Therefore, an individual node chooses his trusted contacts to act as intermediaries for the exchange of data, thus forming a concentric ring. Further rings are built through similar trust relationships, without requiring nodes on the same ring to have trust relationships with one another and without requiring the

transitivity of trust. Data requests are then addressed to the nodes in the outermost ring and are forwarded to the nodes in the first ring along hop-by-hop trusted links. Data are served by nodes in the innermost ring, and replies are sent back along the same paths. PikcioChain thus consists of the collection of concentric layers of peer nodes organized around each individual person or business to ensure data storage and communication privacy. The P2P substrate of PikcioChain is a Distributed Hash Table (DHT) similar to Kademlia (KAD) (Maymounkov & Mazieres, 2002) in charge of storing and retrieving the entry point references of all the nodes' Matryoshkas (individuals' trusted pathway consisting of trusted nodes).

The security and privacy of the system might be compromised if malicious entities were able to impersonate legitimate ones. Malicious entities would then be able to intrude into the rings surrounding a target victim and derive the trust relationship we aim to protect. As a consequence, a mechanism ensuring individual authentication has been used. In PikcioChain, a trusted identification service (TIS) that does not take part in the network itself provides individuals with unambiguous certified identifiers associated with their real identities. Such a TIS does not conflict with the purpose of decentralization, as it can be implemented in a decentralized fashion. The TIS is not involved in any communication or data management operation among the participants, is contacted only once, and can be provided off-line. Finally, classical encryption techniques have been adopted to ensure data confidentiality and data integrity.

In addition to the detailed description of PikcioChain above, we have looked at this specific technique of blockchain compared to other existing ones on the market, and the table below explains the differences based on specific characteristics. Indeed, one of the marked advantages of PikcioChain for our application is the fact that it enables the certification of the users' identities, which is the first step towards true data security.

Several criteria are often used in the literature to describe the technical characteristics of a blockchain:

- The type: this characteristic defines whether a blockchain is public, private or permissioned

- Block production time that defines the duration needed to close or validate a block,

- The duration of a transaction,

- The level of security.

Based on Hyperledger, Pikciochain differs from other blockchains on the market mainly in terms of identity management and the peer to peer approach. . The rest of the comparison between Pikciochain and popular blockchains, such as bitcoin, Ethereum and Hyperledger, is described in Table 7 according to criteria listed above.

Table 7. Comparison of blockchains

Criteria	PikcioChain	Bitcoin	Ethereum	Hyperledger
Type	Permissioned	Public	Permissioned / Public	Permissioned / Public
Block production time	15 seconds	10 min	15 seconds	Transaction time
Transaction per second	200	7	17	3000

2.3.3 Building, intervention and evaluation

Based on the shortcomings of the existing tools for the reporting of drug allergies and based on the reflections carried out in the previous steps to clarify the problem and develop a clear strategy to remedy it, we have approached the intervention stage with the proposal of functional specifications. These specifications were discussed during several exchanges among the different actors of the project before being validated. These exchanges took place between the allergists, the university research team in information systems and the company Pikcio, they consisted in sessions of work around specifications, analysis and mockups.

In terms of evaluation, we achieved usability evaluation with users. Indeed, usability, which is often called user experience by some authors (Albert & Tullis, 2013), must be taken into account throughout the project cycle to avoid the extra costs of redeveloping new interfaces (Virzi, 1992). During this project, one of the goals was to iteratively improve the interfaces of the application. Therefore, we undertook the evaluation of usability to identify potential errors or difficulties that users will face when they navigate the application. Heuristic evaluations of

user interfaces (Scapin & Bastien, 1997) and user tests (Bangor et al., 2008) are important and will be used in this project. However, at the mockup stage, we only conducted user tests with patients and physicians. All interviews were recorded and transcribed (Interview guide in the appendix). We interviewed approximately twenty (20) users, including five (5) physicians and fifteen (15) patients. We use content analysis method to analyze the outcomes and we clustered all the interviews in topics.

2.4Results

The current process described above with regards to drug allergies shows that there are several actors who are potential sources of allergy information, and they must share information with each other to ensure patient safety. It can also be noted that, depending on the actor who reports the allergy, the rest of the process can be different. Starting from this process, we first present the problems identified before presenting the stages of reflection, building and evaluation that followed.

2.4.1 Problem formulation

We can summarize the needs using three core topics based on elements related to the current process described above:

- Availability of data; at this level, it is important to keep in mind that the information can be emitted by any actor,
- Support of data with enough details,
- Process of sharing data among actors,

Since we have a problem-driven approach, Table 8 describes how the characteristics of PikcioChain meet the identified needs.

Table 8. From need to blockchain-based solution

Needs and requirements	**Key benefits of PikcioChain**
Empower every user	Decentralized management

Reliably access information when necessary	P2P transactions
Distinction between self-reported allergy and validated allergy	Data certification
Patient and healthcare professional identification and forensic responsibility and audit trail	Identity management,
Data security	Permissioned blockchain, privacy by design

2.4.2 Reflection and learning

Based on these needs and requirements, we have identified the following specifications distinguished by user's profile (see Table 6).

Table 9. A summary of specifications

User profile	Use cases/ scenarios	Description
Patient	Sign up / sign in	The patient is welcomed on his or her first use of the application by an identification form that is partially filled automatically after loading his or her identity document. This document is also used to certify the patient's identity and to recognize him or her in case of reidentification following the forgetting of his or her access codes. After signing up, the patient can sign in with a login and a password.
	Report an allergy	At any time, the patient can report a reaction to a drug by specifying the elements such as date, the reaction time after taking the drug, and the type of reaction, and in the case of a cutaneous reaction, he or she has the choice

		between several images and the ability to load an image of his or her reaction.
	Check his or her allergy information	Whether he or she is the author or not, the patient has access to the allergy information history. He or she can then consult, for example, the information added by physicians.
	Grant access to identified healthcare professionals	The patient is the one who holds his or her allergy information on his or her device, and, if necessary, he or she can give access to a physician. There can be a case in which the patient responds to a request sent by a physician and another case in which he or she spontaneously seeks a physician to whom he or she assigns access rights, for example, on the eve of an appointment.
	Choose trusted third parties to manage his or her account in case of emergency	Unconscious patients cannot manage their file to grant access to a physician, for example. In these cases, the patient is given the opportunity to choose trusted third parties who will be able to manage his or her file.
	Manage trusted third-party account	Each patient has the opportunity to be the trusted third party of another patient.
Physician	Sign up / Sign in	At his or her first visit, the physician must complete an identification form. Physician’s identity information are validated with the national directory of physicians.
	Send an access request to a patient	To access the patient's records, normally, the physician must send a request that the patient can either refuse or accept. If accepted, the data are exchanged between the patient's device and the physician's device without going

		through a centralized server.
	Check detailed information about patients' allergies	For effective patient management, the physician, when given permission, has access to detailed information about the patient's allergy record.
	Report a patient's allergy	The physician can report a reaction to the medication if he or she has access to the patient's file.
	Validate allergy information reported by a patient	Each physician has the opportunity to validate allergy information either based on the history of the patient or different types of test. He or she will then mention if the patient truly has an allergy or not by specifying the validation process used.
	Access the patient file without prior authorization in case of emergency	In the case of a patient's unconsciousness, the law provides for the solutions of trusted third parties and emergency access by the physician without waiting for authorization, provided that this access is truly justified by an emergency.

Therefore, these specifications lead us to conduct the analysis using Unified Modelling Language (UML). We designed the use case, class and sequence diagram as displayed in the Figure 9 and Figure 10 below.

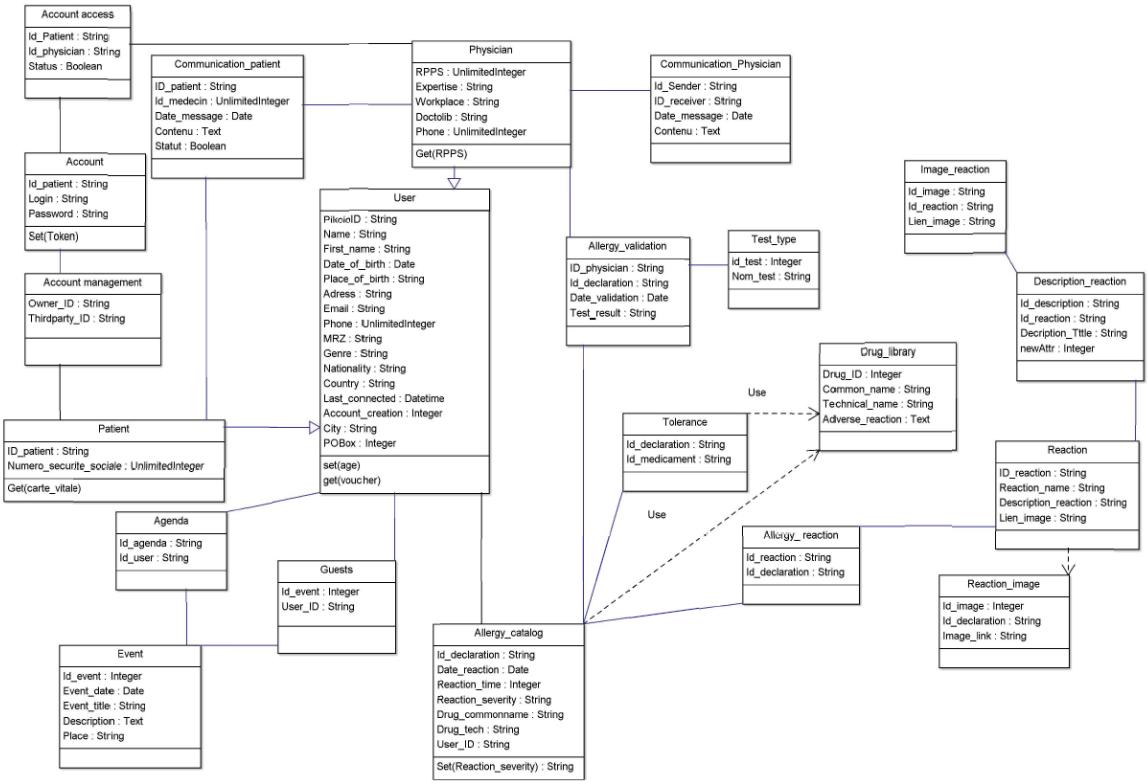


Figure 9. Class diagram

The Figure 9 above shows the structure of data that underlines the application. Therefore, it involves different classes to manage users, feedback, account management by trusted third parties and calendar management.

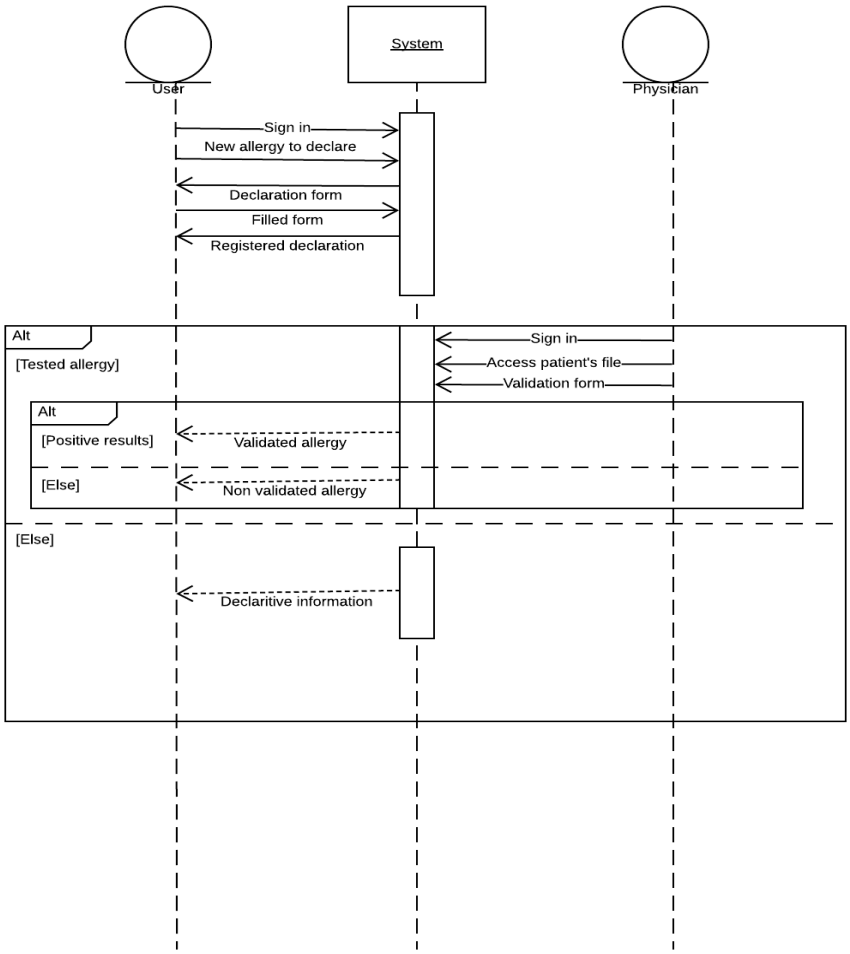


Figure 10. Sequence diagram (declaration and validation of an allergy)

Figure 10 describes the use case of the declaration and validation of an allergy. The declaration consists in the recording of a new reaction and can involve any user, whether he or she is a patient or a physician. The validation part involves only physicians. Depending on whether there are test results, the information on the allergy will have a status “Declarative” or “self-reported”. But before any action, the user must be authenticated.

2.4.3 Building and evaluation

After the analysis phase, we designed interactive mockups with the software Balsamiq cloud (https://balsamiq.cloud). These mockups can show the appearance and content of each page and the general plan of the application. As a result, we were able to represent exactly how each user could navigate the application for each use case stated earlier in this chapter. The interactive mockups allowed us to put the links behind each button to simulate the functioning

of the real application. According to usability best practices, we based our mockups on the interfaces of popular applications such as Instagram. The Figure 11 presents some of these mockups for the patient registration process with all the buttons that are active so that the process can be executed.

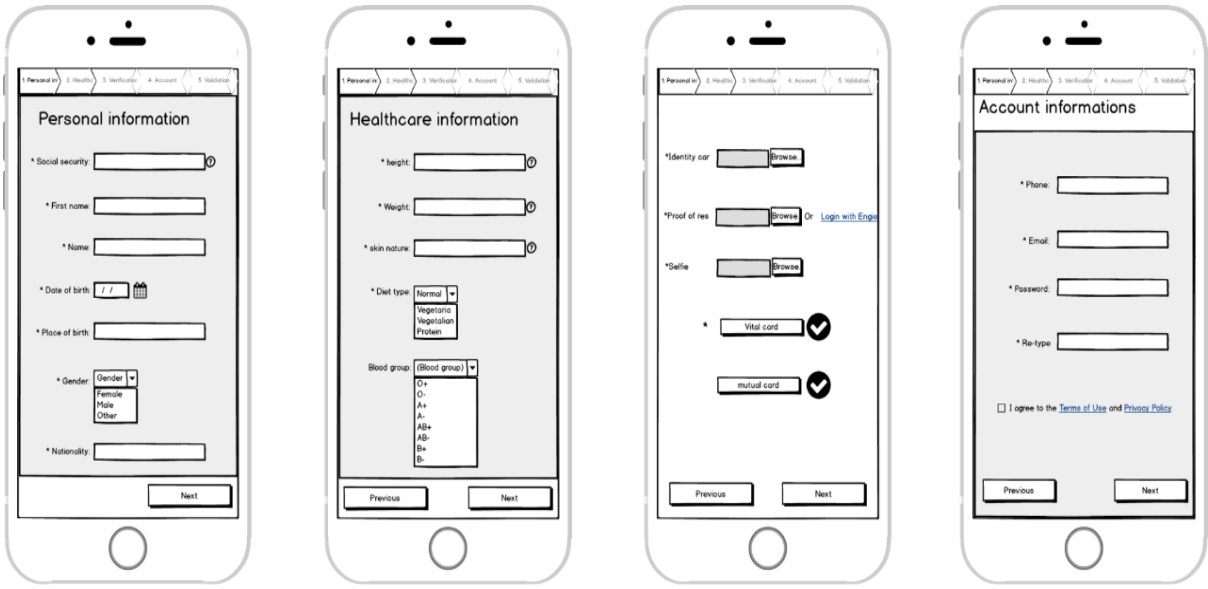


Figure 11. Mockups for the sign up process

In addition, these mockups enabled us to initiate the first usability evaluations. At the same time as the usability evaluations with users (patients and physicians), we also initiated a qualitative study to ensure the clarity of the purpose, the different functionalities and the page contents of the application.

We performed a content analysis of the interview data that we synthesized in Table 6.

Table 10. Interviews analysis

Topics	Patients	Physicians
Purpose of the application	The first part of the questions about the purpose of the application was intended to understand whether patients had an understanding of what an allergy card is	The interviewed physicians see an allergy card as a way to access a patient's allergy history to avoid

	for. Two main profiles of patients emerged: those who currently suffer or have already suffered reactions to a drug and have an allergy card and those who have no idea of what an allergy card is. The first group of patients had a clear vision of what they expect of an allergy card as "a tool to report the allergies of a patient". After reviewing the mockups, some noted that it is good for patients to report information directly after a reaction, even at the risk of forgetting events at their physician's appointment.	administering high-risk drugs to patients. Some physicians have even reported having already experienced situations where, without knowing it, they have administered risky drugs to their patients, which has caused violent reactions.
Contents	It would be good to allow the patient to actually describe the circumstances surrounding his or her reaction to give the most details to the physician.	Regarding the content of the application, the physicians interviewed found some patient identity information useless such as information related to social security number. They also wished to have access to information sources to make it possible to obtain additional information if necessary, for example, by directly contacting this source.
Interoperability	Patients who participated in the study	The interoperability aspect

	were skeptical about building an application detached from the electronic medical records currently used, as they stated that it is better to have all their healthcare data in the same platform.	was also important for the physicians since most of them want to access patient's allergy information directly from their medical software.

As a result, we have an application and a new process in the event of a drug hypersensitivity reaction. The menu of the application on the patient side is composed of tabs: allergy, healthcare professionals, messaging, agenda and trusted third party, as shown in the Figure 9.

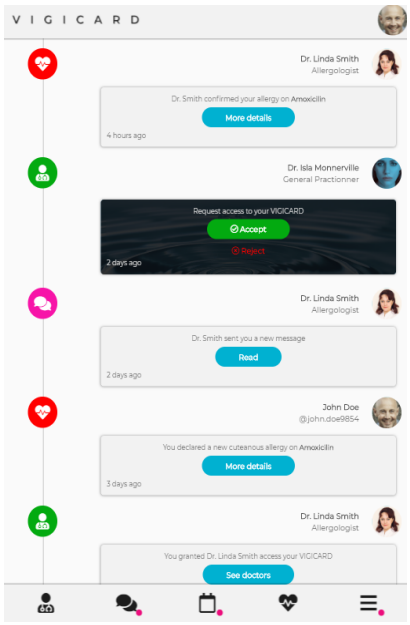


Figure 12. Home page of the application, patient side

On the professional side, there are tabs that include patient, other professional and the agenda, as shown in the Figure 13.

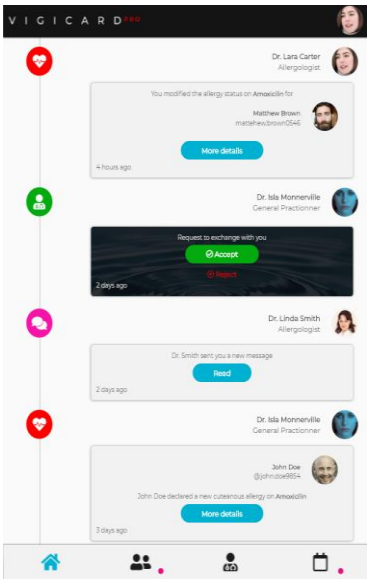


Figure 13. Home page of the application, Physician side

Regardless of the user profile concerned, the default homepage is a newsfeed of the different activities on the account. The process always implies that both the patient and the physician can rearrange allergy information but this time on a device that will allow complete traceability and the logging of all modifications. In this way, the application records the list of allergies as well as details related to each allergy. All changes regarding an allergy are also visibly recorded with the most recent information. The following figures present some visuals of the application in its current state of development.

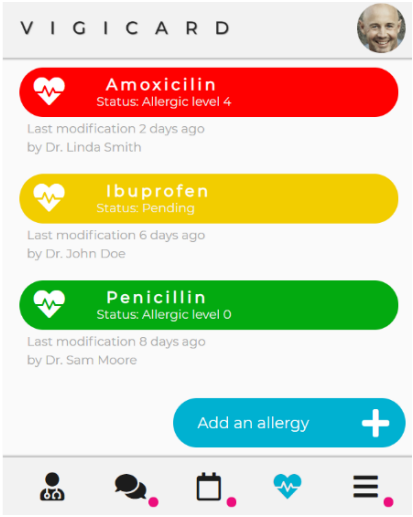


Figure 14. List of allergies

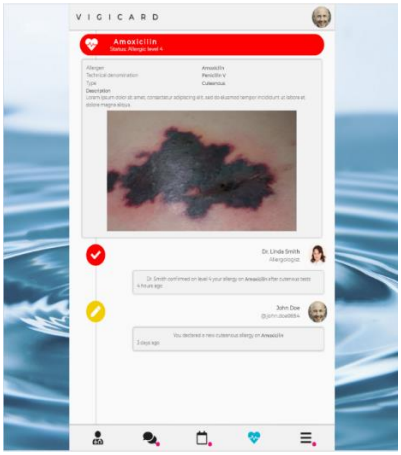


Figure 15. Description of an allergy

Figure 14 above is the page listing the allergies of a patient with a color code to distinguish the levels of validation of the information. Figure 15 presents the details page for an allergy with a history of the various changes that have occurred.

2.5 Implications

This project proposes the modeling and evaluation of the blockchain-based solution (PikcioChain) for the case of an allergy card using a problem-driven and user-centric approach, thus producing proofs of concepts and interesting axes of deployment for a solution that still seems to be missing in Europe.

In addition, this chapter contributes to the blockchain literature, more specifically in healthcare by providing a real-life use case, built to solve real-life issues and involving stakeholder participation in both construction (allergists) and in the field of healthcare. evaluation (patients and Physicians). Concretely, this application will empower patients in the management of their allergies. Patients can easily report suspicions and allergies, enable their physician to directly validate this information in the application and share this information when necessary by granting access to identified users. In this way, it will be possible to have a complete audit trail of information about drug allergies. Physicians will have quick access to their patients' allergy information with details on the level of validation.

2.6 Discussion

The solution that we have presented changes how allergy information management aims to enable an immediate report after a reaction, as well as the ability to easily share information with his or her physicians. From the point of view of physician, the solution allows easy access to detailed and chronological information on of their patients' allergies with the possibility of knowing the owner and the level of relevance of the information (Matricardi et al., 2019). The permissioned blockchain technology and the P2P approach used for data exchange ensure transparency in the system while respecting the confidentiality of patients' personal information. This feature is compliant with GDPR (General Data Protection Regulation) requirements and allows every information owner to delete his / her information when wanted (De Hert et al., 2018). In addition, the careful analysis of the components of our solution reveals the importance of user's identification. Actually, identities are first and foremost, a support for the problem of traceability that the application aims to solve in the sense that they make it possible to ensure that we deal with the right person. Second, user identities are important in the implementation of interoperability, which seems to be a major requirement of health information systems (Sligo et al., 2017). However, our solution uses third-party services to validate user identities; these services also use centralized data structures. This feature may raise questions about the integrity of the identification data at the input. The highest risk in this situation of uncertainty concerns the identities thieves of physicians. Indeed, once the identification is carried out, the application save users logs (complete audit trail of their activity). The solution is the feature of access management that enable patients to grant access to only identified physicians, which still significantly limits impunity identities thieves. Concerning the accessibility of information, we relied on a mobile application taking into account the high adoption rate of smartphones in Europe and worldwide as well as recommendations of the World Health Organization (WHO) concerning mobile applications for the management of drug allergies (Matricardi et al., 2019).

2.7 Conclusion and further developments

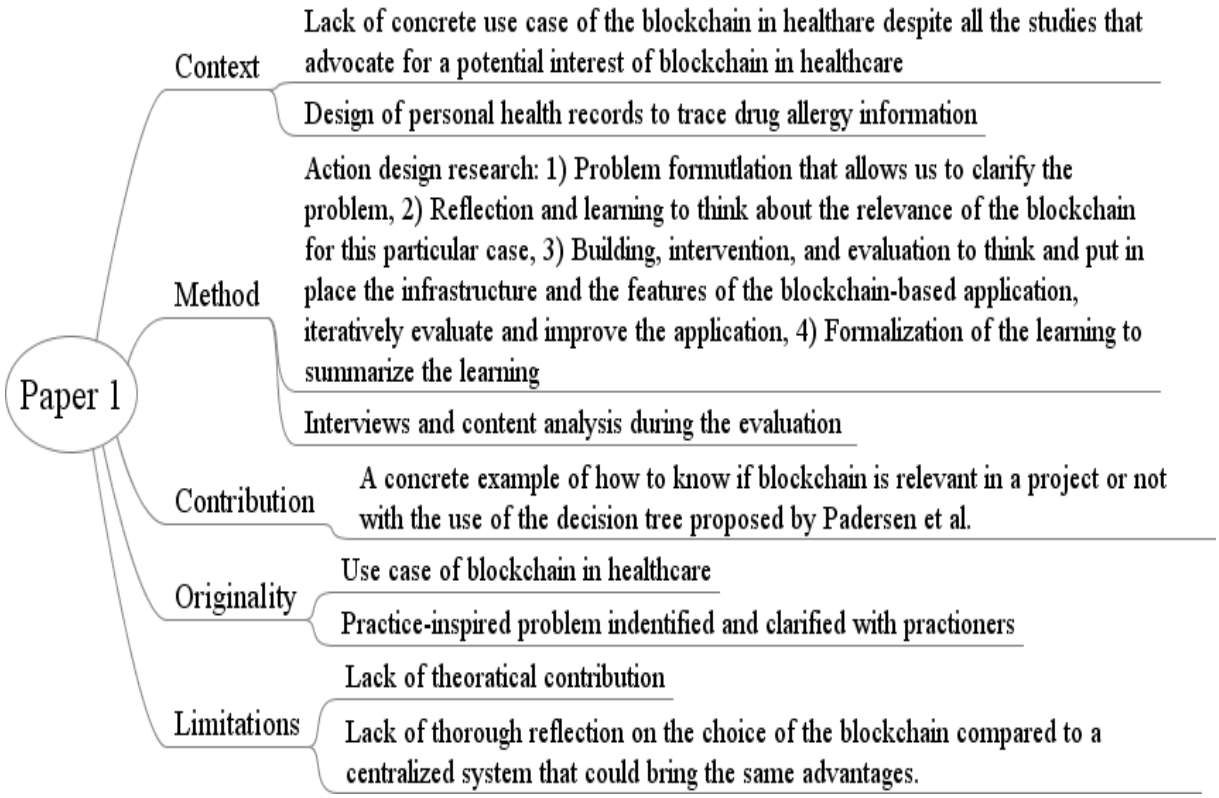
Throughout this chapter, we described how we used the action research design to develop a mobile allergy card application that allows the reporting, sharing and traceability of drug allergy information. The problem has been identified by allergists and clarified and resolved

by an interdisciplinary team to target the real needs of users and respond effectively. Our approach is user-centered because, at each step, user assessments are carried out to ensure that the tool meets their expectations and that problems are solved. We then plan to perform other large-scale usability and quality assessments to improve the interfaces and the content of the application and thus make it easier for users to get started with the tool. Similarly, a clinical study will be conducted to evaluate the impact of the application on the well-being of patients. In addition to the existing functionalities, we plan to add the possibility for patients to agree to anonymously share their data for clinical research. This will have the advantage, in addition to advancing science, of providing a clearer idea of the prevalence of drug allergies through statistical studies.

3. Synthesis and articulation

The writing of this chapter commenced with the observation that, despite the numerous papers that have been published in the context of blockchain in healthcare, there was a lack of concrete use cases proving its feasibility (Hölbl et al., 2018). The goal, then, was to explore the feasibility of blockchain in healthcare.

Figure 16. Synthesis of the paper 1



The drug allergy case we use in this chapter is justified by the identification of a field problem with allergists at the University Hospital of Montpellier.

Blockchain was presented during numerous discussions to clarify the problem. Thus, the allergists, in collaboration with a technology company and information system researchers, got together to propose applying blockchain to this healthcare use case.

Overall, we followed the same steps as an application development project using the ADR framework, which is a design science research methodology adapted for practical problems

(Sein et al., 2011). First, we worked to better understand the problem and the blockchain. Then, we used a decision tree to test whether or not it would be relevant to use blockchain in this specific use case (Pedersen et al., 2019). As a result, we concluded that blockchain would be a beneficial in managing the multitude of stakeholders, the traceability, and the reliability of drug allergy data.

After validating the relevance of blockchain for this use case, we tested its technical feasibility. At this level, the technology company proposed, in accordance with the functional and technical specificities of the application, a multi-layer architecture showing how the blockchain could be integrated into the tool. Throughout the process, two rounds of evaluation were done with users (patients and doctors). During the discussion with the interviewees, we explained to them the purpose of the application by mentioning the blockchain that we integrated in the background. It appeared that very few people knew the importance of blockchain, and in general very few were even interested in the technical tools. The most important thing seems to be the concrete result in terms of maximizing the benefits and minimizing the risks.

Generally speaking, what emerged from the interviews as a potential benefit of blockchain is the reliability, accuracy, and integrity of data during exchanges between stakeholders. Indeed, the reliability, accuracy, and integrity of data is integral to the therapeutic decision-making process to the point where the fear of not having reliable data represents a great blockage for the use of PHRs by physicians. At this level, blockchain seems to bring a plus because it allows the maintenance of a level of trust in the data in an environment where actors have concerns about this issue. However, a pertinent remark that made us think at the end of the 2019 R&D conference was the fact that we had to make sure that what we wanted to do with blockchain could not be done by a simple centralized system. Moreover, the reliability of the data that the blockchain is supposed to bring is not certain because it remains dependent on the reliability of the initial data. These comments led us to deepen our thinking on the needs and the utility of blockchain.

From these comments, we noticed that, despite our efforts to use blockchain according to the needs that arose, we neglected the real needs to “force” the integration of blockchain in our case study.

The reflections carried out during the writing of this chapter were critical for the continuation of the project. They allowed us, among other things, to put the emphasis not on blockchain as an end in itself but as a response to the needs of individuals. The rest of this thesis presents three other papers that focus on the two main challenges we identified during the interviews. These two categories relate to adoption and information quality.

PAPER 2:

“An action design research to facilitate the adoption of personal health records: The case of digital allergy card”

1. Information about the paper

This paper follows the previous one because it has grown out of the reflections we made during the writing and with the different scientific and professional comments we received.

Title	An action design research to facilitate the adoption of personal health records: The case of digital allergy card
Authors	Rhode Ghislaine Nguewo Ngassam, Linnea Ung, Roxana Ologeanu-Taddei, Jorick Lartigau Pascal Demoly, Isabelle Bourdon, Nicola Molinari, Anca Mirela Chiriac
Status	Accepted for publication in the Journal of Organizational and End-User Computing (JOEUC)
Access	Not yet available online
Related communications	Conference Association Information Management (AIM) 2020 (see Appendices – self-authored communication) European Federation for Medical Informatics Special Topics Conferences (EFMI STC) 2020: "Digital Allergy Card: Design and users' perceptions"
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, we conducted interviews with patients and physicians as part of the evaluation of the digital allergy card mock-up and the

	first prototype. As results, we 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	digital allergy card, drug allergy information, action design research, adoption, business process model, mock-Ups, personal health records

Firstly, since the importance of the issue of adoption came up in the interviews without being our focus in the previous paper, we have chosen to focus on this issue from the same data. The reflection on this subject began with a paper published as a single author at the AIM conference. This paper (available in the appendix) was a beginning of a reflection on the issue of adoption in a design process, and we proposed principles from the literature. During this time, we developed another reflection around user perceptions based on feedback from interviews. It is this reflection that we presented at the EFMI STC 2020 conference. We combined the two reflections to write this paper, which was accepted for publication in the *Journal of Organizational and End User Computing* after a 10-month review process.

2. Accepted text

2.1Introduction

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 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.

The research on PHRs is varied 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). This model has 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 (H. 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 by structural equation modelling. 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 the users' perception of PHRs (Archer & Cocosila, 2014; Gagnon et al., 2016). According to several authors, the results of these studies should inform the design of apps that overcome the problems they predict (Benbasat & Barki, 2007; 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 the 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., 2016b; 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 the 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 digital allergy cards (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 in order to make the optimal therapeutic decision. Indeed, problems with allergy information can cause serious harm, especially drug allergies, which require special attention from doctors—mostly family practitioners—when they make a prescription (Dworzynski et al., 2014; Villamañán et al., 2011). These problems can be either underdiagnosis—where an existing allergy is not considered due to unavailable or inaccessible information, which causes the administration of risky drugs that can lead to very serious reactions and even the death of the patient (Ferner & McGettigan, 2020)—or overdiagnosis, which manifests when the label "drug allergy" is wrongly attributed to a patient, leading doctors to prescribe alternative drugs that are more expensive and less effective (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 the Action Design Research (ADR). This method contains several steps: 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 highlights the main contributions in terms of the developed app's ability to optimize the management of drug allergies and the research propositions.

2.2 Literature review

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

2.2.1 Background on 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 (H. 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). In both cases, the PHR is kept secure and private. 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 ones being patients and individuals who are empowered to self-monitor their health (Gagnon et al., 2016). Physicians are also important in supporting individual's 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; H. 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 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 (H. 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 (H. 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 doctors 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 non-use, misuse, or workarounds (Laumer et al., 2017).

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 the 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.

2.2.2 Action design research

ADR draws its theoretical foundations from research in design sciences that seeks to develop prescriptive design knowledge through the building and evaluating 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).

Design Sciences Research (DSR) has its origins in artificial sciences (Simon, 1980). Several scholars working on design sciences support research in information systems for their applicability in innovative IT design (Benbasat & Zmud, 1999). Therefore, beyond explanatory, analytical, and predictive theories, researchers in information systems have been interested for several years in theories for design and action to define a precise scientific method to solve an identified class of problems (Spagnoletti et al., 2015). A class of problems represents a broad category of problems that can manifest empirically in various environments. Thus, a researcher in design sciences must deduce some knowledge from the solving process of a problem, which can enrich the literature used to inform or solve the identified class that encompasses the identified problem (Hevner et al., 2004).

Moreover, the outcome of a DSR can be an artifact and the prescriptive knowledge that arises from the design process and use of that artifact (Hevner & Chatterjee, 2010). 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 DSR, as defined by Peffers et al. (2007), the evaluation process occurs after implementing the artifact in the organizational context (Gregor & Hevner, 2013). The result is that the design process and evaluation process are separated (Hevner et al., 2004). This approach evolved into ADR, which 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 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). ADR has 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. This method is particularly suitable for complex contexts such as health care (Sherer, 2014), a field that involves several stakeholders, including patients, physicians, policy makers, and IT providers (Payton et al., 2011). The complexity of this context is related to the specific characteristics of medical specialties, patients, and their diseases, which make it impossible to standardize the planning of medical processes such as making a diagnosis or a prescription (Abernethy & Stoelwinder, 1990; Lunenburg, 2012).

2.3Research design

This research project was initiated in March 2019 by an allergist and a researcher in information systems (authors of this paper). After that, the hospital allergy unit manager and researcher in allergology was 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 (

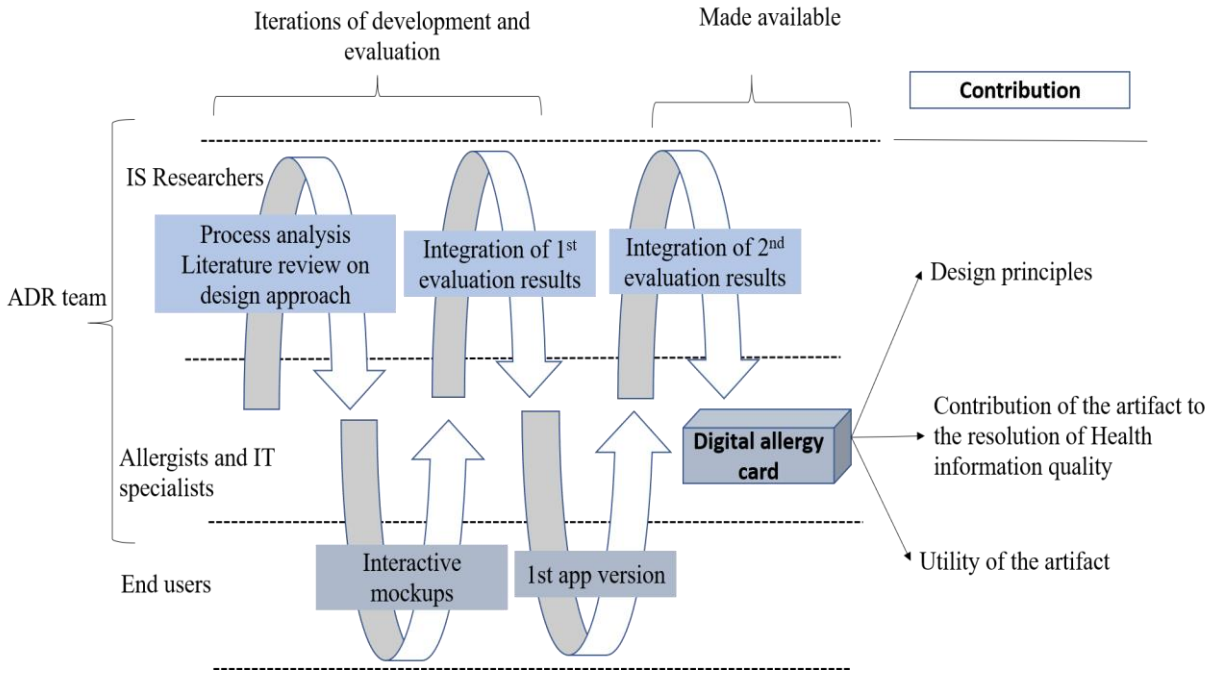


Figure 21. Action design research cycles

displays the research design).

2.3.1 Context of drug allergies and the relevance of a digital allergy card

Drug allergies affect about 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 doctor 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 or not to continue the drug based on the risk/effectiveness ratio (Ferner & McGettigan, 2020). Therefore, allergy information must not only be accessible, but it also must 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 (under-reporting) and overdiagnosis (suspicion of allergy—for example, based only on a patient’s clinical history) may lead to the re-administration 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 (DHR). 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 of “drug allergy” itself corresponds to immune reactions, and in cases of low severity and lack of proof (i.e., no allergy work-up), a doctor 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 doctor 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 doctor, 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).

2.3.2 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. **Erreur ! Source du renvoi introuvable.** 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, simulating, and executing of processes (Lin et al., 2002; Qingzhong et al., 2003). The project team used the software Bizagi 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 doctor. The doctor can either directly consider the information as given by the patient, ask further questions to the patient, or test the patient to ensure the consistency and possibility of an allergy. The doctor can then ignore the information by not reporting it, record the information in the internal EMRs, 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 EMR or establish a paper card. Regardless of the situation, the information on the allergy, when it exists, must be shared with the doctor 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 be inaccessible to a doctor who needs it at any time in the process. The DAC would simplify the process for both doctors 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, doctors, and trusted third parties.
- The patient, doctors, or trusted third party can report an allergy reaction.

- The information can be labelled as "self-reported," confirmed, or denied. The first label is for allergy data that is not validated by a doctor. For the two last labels, the doctor 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 doctor 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.

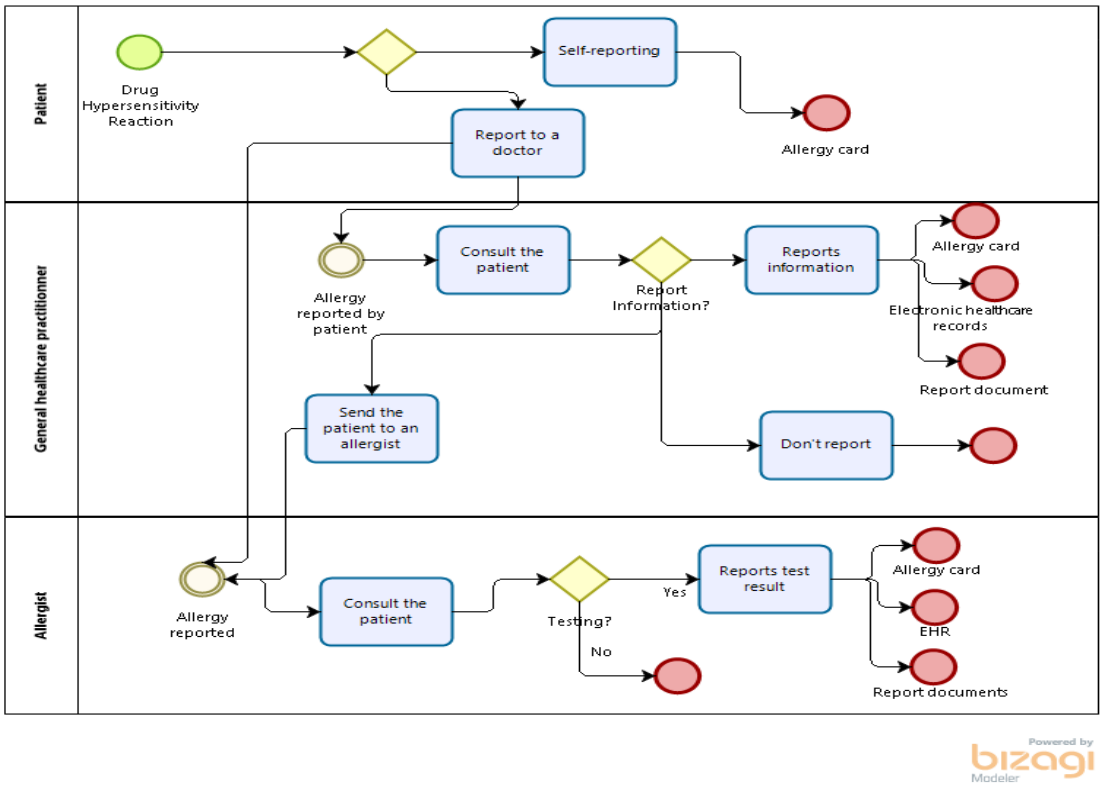


Figure 17. Process of clarifying drug allergy information

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

2.3.3 Stage 2: Building, intervention, and evaluation

This stage includes the modelling of the solution, the development of the application, and the presentation of the user assessment.

2.3.4 Solution modelling

Starting from the BPM and the specifications identification, we moved to technical modelling using a specific technique called the Unified Modelling Language (UML), which is a general-purpose developmental modelling 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 the Argo UML software to model the class diagram, the use case diagram, and the sequence diagrams for each use case, in order to move from user language to a technical language that is easily understood by developers (Medvidovic et al., 2002).

After the analysis phase, the authors designed interactive mock-ups (see

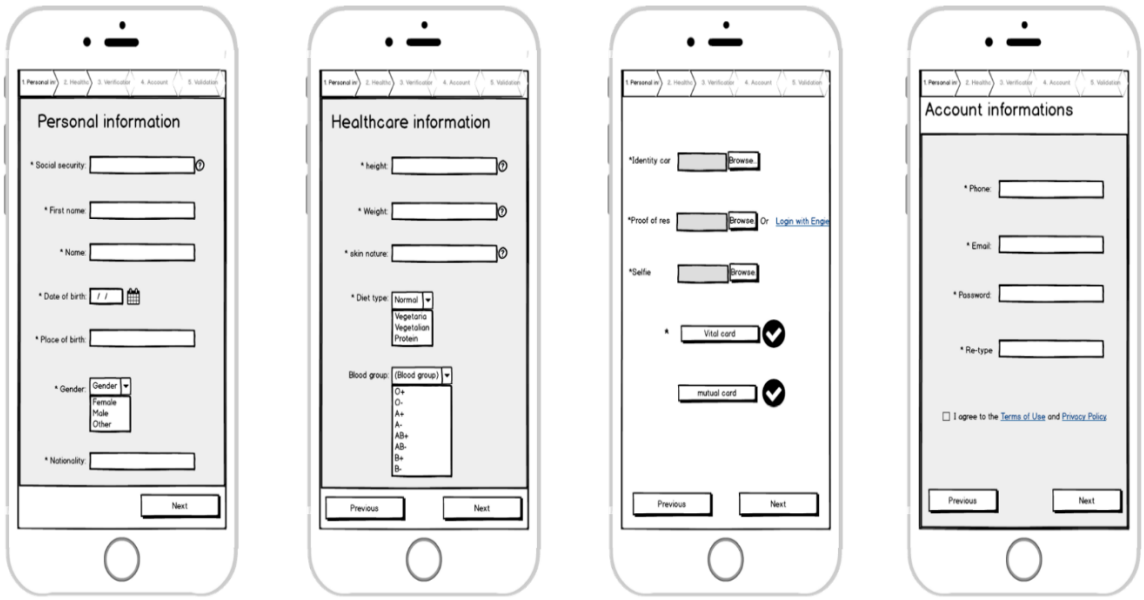


Figure *18*) with the web app Balsamiq Cloud (https://balsamiq.cloud). The mock-up shows the appearance and content of each page and the general plan of the app. This makes it possible to present an aspect of the application to users without having to actually code the interfaces. While diagrams generally represent the back end of the application, mock-ups allow for the representation of the front end—i.e., the layout of the functionalities, the tabs, etc.

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

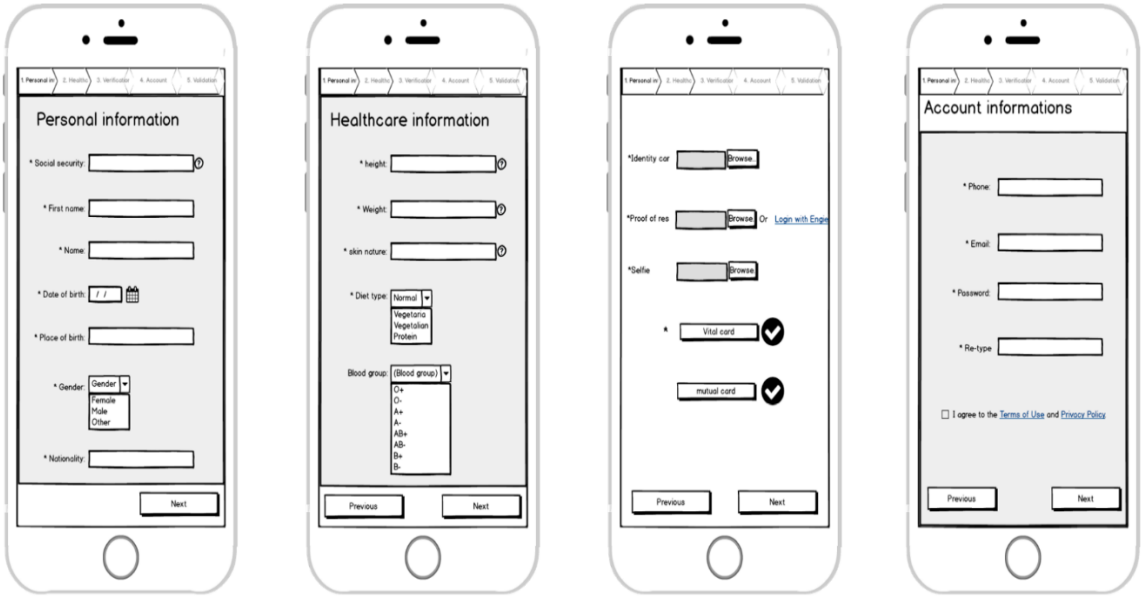


Figure 18. Interactive mock-ups

2.3.5 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 doctors. The DAC that we designed and developed in this study (see Figure 19) 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 authorized doctor, or a trusted third party chosen by the patient. A color code (similar to stoplights) 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 doctor, it remains in the self-reported information category, represented by the yellow color (“suspected, not confirmed”).

The second feature allows a doctor 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 doctor. The third feature allows patients to grant access to specific users. This refers to giving access to doctors 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.

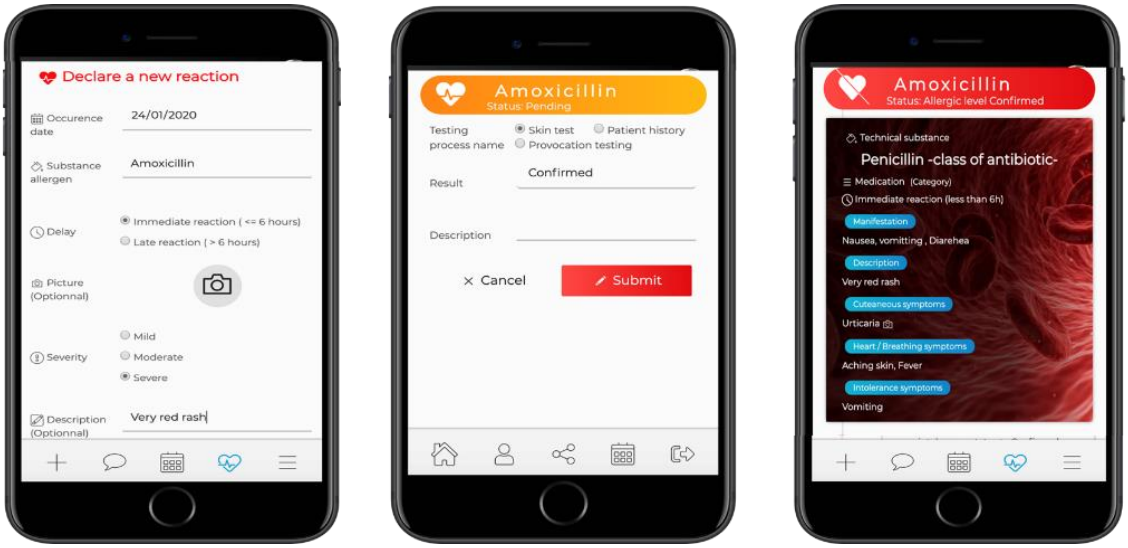


Figure 19. App interfaces

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 in the public interest because all individuals can be affected (Demoly et al., 2014). However, aside from the allergists who were involved in the needs assessment, the public opinion is largely unaware of the specification of the DAC. 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 doctors. 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).

2.3.6 Data collection and analysis

Data were collected by semi-structured 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 doctors and eleven 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 the 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 doctors) using an inductive thematic analysis, which is inspired by grounded theory (Corbin & Strauss, 1990). All interviews and "think-aloud" comments were assessed by 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 consensus was achieved (Zwaanswijk et al., 2011). Later, we interpreted the results by analyzing the links between the different interview data.

Table 11. 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. And of course, specify the molecule. Already have a lot of details on allergen." – Patient 5 "I will just put Allergies and then whether it is validated or not by the doctor." – 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. Also, 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	The DAC provides proven allergy information	

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		
"He contacts me directly, within the hour." – Doctor 1	The DAC allows fast patient/doctor communication, usually within an hour	
"This app can guide me to inform differential diagnoses." – Doctor 2	The DAC allows a 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 doctors, 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 doctor, yes." – Patient 1	The doctor'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. But, if for example, I find that 40 to 45% of people are already registered, yes." – Doctor 3	The fact that patients use it will make it easier for doctors to use it	

"Yes, but not even that. I have a problem I have my family doctor, 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
"But a bit 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." – Doctor 5	Too long of a registration time can discourage doctors 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
". . . But 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?" – Doctor 4 "He should be able to put an episode on the same page. So, we have all the follow-up for the same drug." – Doctor 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?" – Doctor 4	Integrate the scan of cutaneous test results	

2.4 Results

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

2.4.1 Stage 3: Reflection and learning

DAC content

For patients and doctors, the DAC represents an app containing identity information and the details and the 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, the allergy information would also be made more accessible through the DAC, allowing doctors 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 doctor. The last aspect of the usefulness of the DAC that emerged from the interviews is the communication between patient and doctor. However, this point of view is not shared by some patients, as one expressed her difficulty with contacting doctors because of their busy schedules.

Facilitators for the adoption and use of the DAC

For patients, the facilitators for adoption and use may be relative 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 doctor could incite some patients to adopt and use the DAC.

For doctors, 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.

Suggestions for DAC improvement

Patients and doctors 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 the status of validation) 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 is validated.

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

2.4.2 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.

2.5 Discussion

The purpose of this study was to provide actionable knowledge for the development and the 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 by 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 done 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 doctors have identified the proof of allergy information as a potential benefit of the DAC; therefore, we have integrated in the specifications some features to allow doctors to validate an allergy information after a cutaneous test or another appropriate clinical procedure.

The evaluation with patients and doctors highlighted several aspects that make the DAC similar to a PHR. The main factor is the accessibility of allergy information, which patients and doctors 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 doctors 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 doctors; and the paper card (Roehrs et al., 2017), which can enable the same level of accessibility if the 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.

The access to the DAC by the doctor can be done by two methods. The first is directly on the app by creating an account and authorizing access by the patient whose file the doctor wants to consult. The second method is directly on the doctor's workspace. This solution facilitates access in a short time. Indeed, to enable doctors to perceive the benefits of information accessibility, this accessibility must be easy and fast in cases of emergency and to 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 doctors 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, doctors are concerned about the accuracy of this information. In the case of drug allergies, doctors 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, like with PHRs, patients and doctors 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 (N Archer et al., 2011; Roehrs et al., 2017), the evaluation feedback do 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 get 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 suggested should be integrated into the app according to the patients feedback. However, our evaluation has shown that this empowerment is not important for some patients; rather, they prefer to rely on doctors for the management of processing 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 doctor'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 the 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, 2009a).

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 contribution is in how we extend 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 would influence each other in the decision to adopt a PHR. While physician's 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, person) surrounding the individual at the time to use the service. Another suggestion 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.

2.6 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 doctors. 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.

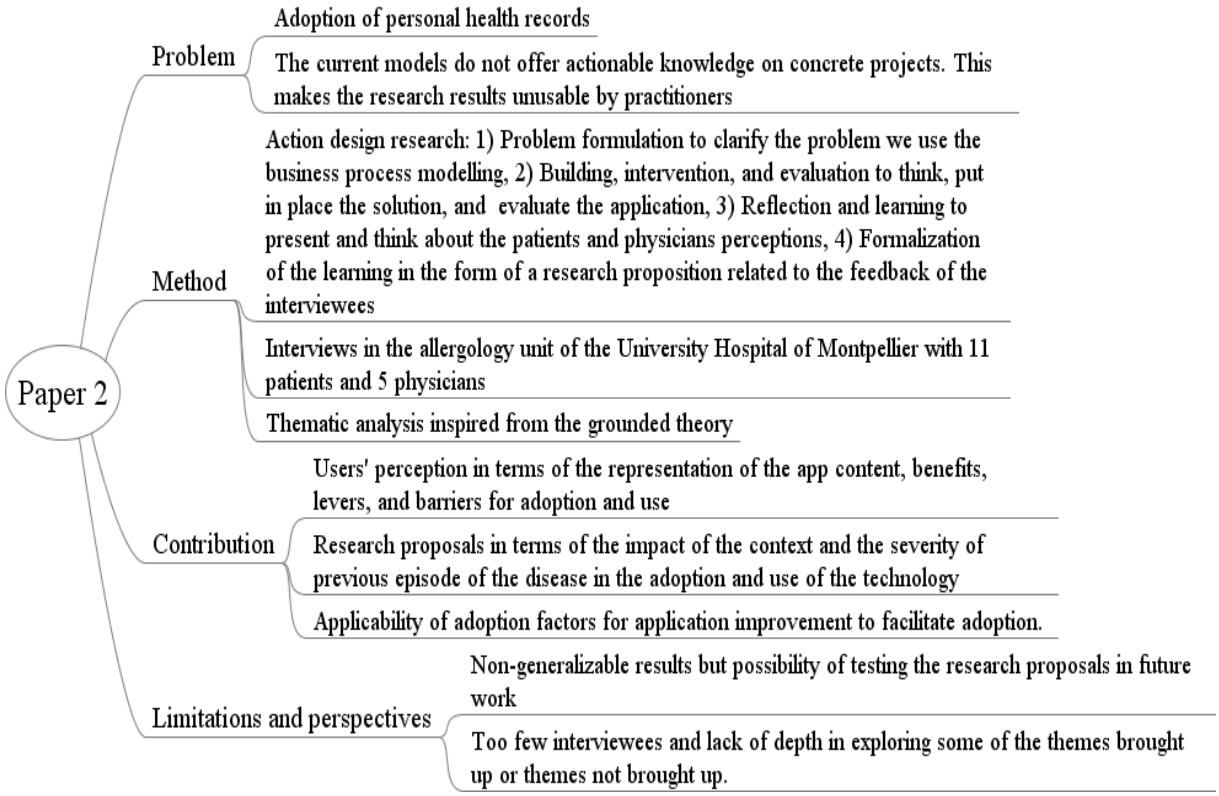
We found that patients and doctors see the DAC as a PHR with the capability of addressing issues related to the availability, completeness, accessibility, accuracy, and reliability of the information. Elements such as the prevention of emergency, the severity of previous experiences with allergies, or the expectation of the doctor's opinion before using the app appear to be facilitators for the app's use, while the complexity of ergonomics and the long use time 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.

3. Synthesis and articulation with the thesis

In this paper, we use the ADR framework to propose actionable knowledge for the adoption of a PHR. We use the case of the drug allergy card as an instance of PHR.

Figure 20. Synthesis of Paper 2



First of all, we noticed that the adoption problem has been widely studied in the literature but that the knowledge we have is very limited due to the difficulty in figuring out how to apply this knowledge in concrete cases.

Then, during the interviews, while evaluating the app, patients and physicians raised some interesting points that allowed us to better understand the adoption issue and to cope with issues around applicability—for example, the construct perceived benefits often mentioned in the literature as a positive determinant for adoption. These interviews helped us better understand how such benefits can be practically used during a specific project. Taking our use case, patients have raised several potential benefits of the DAC on their healthcare pathway.

These clearly mentioned benefits go beyond the general knowledge we have in the literature. Indeed, beyond knowing that the application would make information accessible, exhaustive,

or reliable, we could know how to get there through specific features of the application we were designing.

Beyond that, this study highlighted the fact that often, even when the application has everything it needs to be useful, it is not of great interest to some individuals in contexts where there is no real need for it. This allows us to project ourselves in a concrete way and to better understand our market.

We have taken the example of benefits, but we could take the example of barriers to adoption that we have identified or incentives for adoption, such as physician recommendation.

More concretely, this paper has allowed us to deepen the reflection on the issue of PHR adoption by highlighting details that TAM or UTAUT models or classical studies on adoption do not specify (Benbasat & Barki, 2007). This paper also helped in the general construction of the thesis, one of the elements of relevance of which is the interdependence between the behavioral sciences and the design and action sciences. It is within this framework that, in order to validate and propose a generalizable knowledge, we use elements of the results of this paper for the construction of paper 4, which outlines an experiment that aims to test the importance of context in the adoption of PHRs.

PAPER 3:

“Affordances-based approach to health application design to improve the quality of health information: the case of a digital allergy card “

Paper 3 – affordance-based approach for e-health application to enhance information quality

1. Information about the paper

The reflection on this paper was done in the context of deepening our understanding of ADR as a method to solve practical problems.

We came to reflect on the quality of the information in considering that the problem was related to different aspects of the allergy information.

This paper was presented in an AIS scientific paper development workshop (DITE 2020 SIG). It was also presented at ECIS 2021.

Later, we submitted to *BISE*, but it was rejected. We are using comments from this rejection to improve the paper. Our new target is the review *CAIS.*

Title	Affordances-based approach to health application design to improve the quality of health information: the case of a digital allergy card
Authors	Rhode Ghislaine Nguewo Ngassam, Roxana Ologeanu-Taddei, Isabelle Bourdon
Status	In progress after a first reject at BISE
Access	-
Related communications	Workshop SIG DITE (a special interest group of the Association for Information System (AIS)): Development and validation of a Digital Allergy Card (DAC) ECIS 2021: Design of health application to enhance health information quality: the case of a digital allergy card
Abstract	Despite its importance for decision making, existing studies on information quality do not address the related problems in a concrete way. We propose to use the affordance perspective to define information quality as the result of interactions between the user and the system and to deduce key affordances that allow interactions to contribute to higher quality of information in the system. This approach is new because it complements other

	studies more focused on evaluation and analysis frameworks of information quality. We have used the affordance perspective in an action design research procedure, and this led to the deduction of five (5) design principles that allow us to answer our research question and that could be tested in other mobile or web application development projects.
Keywords	Digital allergy card, Health application; Action design research, Affordance-based; information quality

2. Current version of the paper

2.1 Introduction

The information was presented in information systems and several other areas as the raw material for decision making. The quality of information was addressed in this framework as a prerequisite for organizational performance and individual satisfaction. Therefore, a rich and extensive literature exists for the analysis and evaluation of information quality.

Information quality is a multidimensional concept that defines the intrinsic characteristics of information, its value concerning a specific use, and the link with the digital application that contains it (Lee et al., 2002). The literature presents the various recurring problems of information quality that have economic, financial, managerial, and even human repercussions when considering fields such as healthcare.

To overcome these problems, companies have focused on IT-related transformations with the aim of providing the best possible framework for the information life cycle. Therefore, several projects for the development and implementation of information technology in organizations have been launched. In the same vein, several IT applications for individuals have been launched on the market. Several authors specifically point out that computerized information systems are more effective in addressing information quality problems than paper-based information systems.

Accordingly, the literature reports several studies that analyze information quality's impact on system quality (Delone & McLean, 2003). Several other studies develop methods and frameworks for assessing information quality (Gorla et al., 2010). These various studies suggest a link between information quality and IT applications and a link between information quality and the user. However, these links remain abstract and non-actionable. Yet, a more concrete view of these different links would allow one to better address the issue of information quality when correcting or preventing information quality problems in IT projects. Moreover, the extensive literature on information quality has actually aimed to identify clear improvement points to initiate corrective actions (Gorla et al., 2010). One area for information quality improvement is, for example, improving the quality of the system or digital application that contains the information. Decision-makers could do this by emphasizing up-to-date hardware and software, graphical user interfaces, and well-designed

and well-documented systems (Gorla et al., 2010). However, the current state of knowledge does not clearly allow concrete actions to be put in place to prevent or correct information quality problems. In other words, the existing literature makes few "relevant" practical contributions according to the definition of Jabagi et al., i.e., presenting arguments that are persuasive (incite action) and easily assimilated by actors in the field (applicable and accessible) (Jabagi et al., 2016a).

The objective of this study is to propose an actionable view of the links between users, IT applications, and information quality in order to provide knowledge that can be used by field actors in design, development, and improvement projects of IT applications. Therein, we propose the following research question: How can we extend current knowledge related to the links between the users, the system, and information quality into actionable knowledge so that it is easier to take preventive and corrective action on information quality problems in IT projects?

Recently, several authors have shown interest in using the concepts of affordance and affordance actualization to identify the mechanisms and contextual conditions of an observed phenomenon according to a critical realist approach (Buchana et al., 2018; Bygstad et al., 2016). Volkoff & Strong (2014) have positioned the analysis of affordance actualization as actionable, because then it could guide an intervention in the field. Moreover, affordances have been identified as a second-order variable in the relationship between the quality of the system and the quality of the information (Grgecic et al., 2015).

In this sense, our study aims to propose an actionable view of the links between user, digital application, and information quality using the affordances approach. Indeed, affordances define the relations between several subsystems that can lead to an action that could not take place with a single subsystem. For example, with the case of a digital application, the affordance of "information entry" defines a possible relationship between the user who holds the information and the application in which the information must be entered.

Our study is carried out through the design of a mobile health application. We chose the design phase because it allows us to prevent information quality problems rather than correcting them at a much higher cost after implementation (Mettler, 2016). We chose the health field because laws and regulations, as well as individual concerns, force mobile health

application developers to pay close attention to the quality of health information, which is very sensitive since it directly affects the safety of individuals.

The following sections successively present the different concepts and the theoretical framework used, the methodology, the results, the discussion, and the conclusion highlighting several research contributions in the literature on information quality and on the methodological level of design sciences by bringing in the affordances lens to create actionable knowledge of information quality in design projects of digital applications.

2.2 Previous literature

Health information is at the center of health discussions, especially when it comes to health applications. Indeed, several studies related to health applications raise the question of health information quality (Buntin et al., 2011; Cruz-Correia et al., 2013; Kohli & Tan, 2016; Tang et al., 2006).

This section will first present the related literature on information quality in IS. Then we will present information quality as a result of system quality and the interactions with the system.

2.2.1 Information quality in IS research

Information quality is considered a key element in information system' success, on individual satisfaction, and organizational performance (Delone & McLean, 2003, 2004). Several authors have taken an interest in this concept to measure, analyze, and improve information quality. Some authors have looked at information quality assessment frameworks for different intrinsic, contextual, representational, and accessibility categories of information quality (Lee et al., 2002).

The intrinsic aspect of information quality makes it possible to characterize the information in its own right (Wang & Strong, 1996). This category refers to the extent to which data values are compliant with the actual or true values.

The representational and accessibility categories link information quality with the system or application. Indeed, several authors define information as the system's product or application's outcomes (Gorla et al., 2010; Neely & Cook, 2011). Thus, information quality is an integral part of the system quality (Lee et al., 2002). Some authors advocate for a digital

application to guarantee or improve information quality (Häyrinen et al., 2008). Other authors assess the impact of information quality on the overall quality of the system or the digital application (Delone & McLean, 2003).

The contextual category links the quality of information to the user, the need, and the use of the information (Wang & Strong, 1996). Some authors who consider humans as prosumers (producers and consumers) of information emphasize that the quality of information depends on the interaction between the user and the system (Tilly et al., 2017). More concretely, the quality of information depends on what users have produced when using an application. The response measures the quality of the information consumed at the output of the application it provides to the user's needs.

These different categories are in line with analyzing the quality of information as an antecedent of a system's quality and users' satisfaction. Therefore, information quality is made up of several dimensions (Zhu et al., 2014) presented in Table 12 below.

Dimensions	Definitions	Category	References
Completeness	Refers to whether all of the information relevant to a particular application is present	Contextual	(Cruz-Correia et al., 2013) (Laumer et al., 2017)
Consistency	Refers to an absence of conflict between two datasets	Representational	(Gorla et al., 2010; Lee et al., 2002)
Timeliness	Refers to up-to-date information	Contextual	(Lee et al., 2002)
Availability	Refers to information that authorized users or	Contextual	(Cruz-Correia et al., 2013; Laumer et al.,

	applications can retrieve		2017)
Accessibility	Refers to information that can be processed and read	Accessibility	(Cruz-Correia et al., 2013; Laumer et al., 2017)
Ease of understanding	Refers to information that is easy to interpret the way it is formatted	Representational	(Cruz-Correia et al., 2013; Delone & McLean, 2003; Laumer et al., 2017)
Security and privacy	Refers to information protected from intentional or accidental destruction, modification, or disclosure	Accessibility	(Cruz-Correia et al., 2013; Lee et al., 2002)
Accuracy	Refers to an agreement with a real-world entity attribute, a value stored in another database, or the result of an arithmetic computation	Intrinsic	(Gorla et al., 2010; Lee et al., 2002)

Table 12. Information quality dimensions

Other authors show that these dimensions are of varying importance depending on the field under consideration. For example, while the information format is essential for data science, accuracy is critical for aeronautics or healthcare (Wang & Strong, 1996). In healthcare, the problems with the quality of information can manifest as incomplete, inaccurate, incorrect, unavailable, ill timed, or unclear. These problems are the main cause of medical errors, causing healthcare providers to lack the elements that would allow them to make the right treatment decisions for patients (Gogan et al., 2013).

Several studies related to the evaluation and analysis of information quality have shown that the quality of information should be evaluated according to recipients' needs and application capabilities the recipient actualizes through features (Chaudhry et al., 2006; Gorla et al., 2010; Lee et al., 2002; Shamala et al., 2017).

2.2.2 Information quality as a result of interactions with and within the system: An affordance lens

Information quality issues can arise at any point in the information life cycle (Gogan et al., 2013). Grgecic, et al. (2015) have identified a relationship between an application's functional affordances and information quality.

Indeed, the relational dimension of affordances is described by Maier and Fadel (2009b) when they define affordances as "a relationship between two subsystems in which a potential behavior can occur that would not be possible with either subsystem in isolation."

The affordance's characteristics show more clearly their relational dimension (Maier & Fadel, 2009b). The first characteristic is complementarity, meaning that an entity in isolation cannot enable the actualization of an affordance. Moreover, affordances can also be complementary with each other—i.e., an affordance actualization could depend on the preliminary actualization of one or more other affordances (Oborn et al., 2011; Strong & Volkoff, 2010). The second characteristic is polarity, which implies that the designer should ensure both positive and negative affordances. In the same sense, multiplicity means that a digital application can allow several affordances (Maier & Fadel, 2009b). Moreover, the quality of an affordance depends on whether the system will or will not support the affordance actualization's behavior. Lastly, affordance depends on the system form (Maier & Fadel, 2009b).

Interactions between the user and the digital application or between several subsystems of the digital application can affect the quality of the information during its collection, processing, storage, or transmission (Gogan et al., 2013). These interactions are completed by affordances actualization (Strong et al., 2014). Indeed, the negative impact of affordances on the quality of information can be due to several factors. Firstly, an essential affordance is not actualized

(Strong & Volkoff, 2010). Secondly, the application designers may not have provided essential affordances or may only have provided incomplete ones (Volkoff & Strong, 2013). For example, an important field may be missing when collecting information, which will make the information incomplete. A third option is that the user may not perceive the affordance. In this case, the problem could be on the application interface (Volkoff & Strong, 2013). The last two cases involve the design phase, since one is missing, and the other is a usability issue. Thus, the design phase is crucial in predicting essential affordances through user-friendly features.

One crucial design exercise is then to identify the affordances and represents them as features on the application (Norman, 1999). We suggest a relational view of information quality by highlighting the link with the relational dimension of affordances. It shows system-users or system-system interaction might impact information quality (Grgecic et al., 2015). More concretely, information quality is a function of the system's capability to support interactions for collecting, processing, storing, and transmitting information.

This section argues that the objective of information quality studies is to resolve or prevent information quality issues in digital applications. We also present the fact that the design phase is crucial in preventing information quality issues.

We use the relational dimension of affordances to inform a digital allergy card's design process to address identified quality issues related to drug allergy information. We use the action design research framework to develop a process followed in the design phase.

2.3 Method

2.3.1 Action design research framework

ADR draws its theoretical foundations from research in design sciences that seeks to develop prescriptive design knowledge through building and evaluating 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).

Design sciences research (DSR) has its origins in artificial sciences (Simon, 1980). Several authors working on design sciences posit that the interest of research in information systems is their applicability in innovative IT design (Benbasat & Zmud, 1999). Therefore, beyond

explanatory, analytical, and predictive theories, researchers in information systems have been interested in several years in the theories for design and action to define a precise scientific method to solve an identified class of problems (Spagnoletti et al., 2015). A class of problems represents a broad category of problems that can manifest empirically in various environments. Thus, a researcher in design sciences must deduce from the process of resolving an example of a broader problem some knowledge that enriches the literature used to inform or solve the identified class of problems (Hevner et al., 2004).

Moreover, the outcome of a DSR 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 also called design principles (Gregor et al., 2020). However, because the fundamental paradigm of research in design science is the resolution of a class of problems, it is essential to evaluate the fit between the proposed artifact and problem, especially in the organizational context in which the problem was identified and the solution deployed (Sein et al., 2011). In DSR, as defined by Peffers et al. (2007), the evaluation process occurs after implementing the artifact in the organizational context (Gregor & Hevner, 2013). The result is that the design process and evaluation process are separated (Hevner et al., 2004). This approach evolved to ADR, which starts from the basis that the artifact is shaped by the organizational context both during the design process and its use after implementation (Sein et al., 2011).

Moreover, both DSR and ADR aim to solve practical problems. The starting point of an ADR process is therefore a practical problem in an organization rather than a theoretical design problem in DSR (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. ADR has two types of actors (Baskerville & Wood-Harper, 1996; Sein et al., 2011): (1) researchers and practitioners who each bring both theoretical expertise for researchers and practical expertise for practitioners in the construction of the artifact and (2) end-users in the organizational context who are involved in evaluating the artifact and considering 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 in the design process to validate the artifact according to their needs (Smith et al., 2020). Thus, the ADR encourages these end-users' involvement from the early stages of the design process to formulate the problem and help achieve the most suitable solution iteratively. This method is particularly suitable for complex contexts, such as healthcare (Sherer, 2014), that involve several stakeholders, such as patients, physicians, regulators, and providers (Payton et al., 2011). The complexity of this context lies in the fact that the needs are difficult to capture given the case-impossibility of capturing a standard process corresponding to the general healthcare context. Mintzberg (1979) refers to this type of context as professional bureaucracy characterized by professionals' autonomy in their work, meaning a routine cannot be established and standardized (Abernethy & Stoelwinder, 1990; Lunenburg, 2012).

Therefore, the ADR approach is suitable for this research. We will perform a case study related to developing a digital allergy card (DAC) to solve an identified problem for drug allergy information as an instance of health information quality. This approach will enable us to iteratively improve the solution regarding feedback obtained from end-users because of the evaluation loops we will perform throughout the process.

The ADR process is a four-staged methodology: (1) broblem formulation, (2) building intervention evaluation (BIE), (3) reflection and learning, and (4) formalization of the learning (Sein et al., 2011). We applied each of these stages as described in the next sub-section**Erreur ! Source du renvoi introuvable.**.

2.3.2 Research design

This research project was initiated in March 2019 by an allergist and a researcher in information systems. Soon, the hospital allergy unit manager, a researcher in allergology, became involved as well. Both allergists worked actively to manage allergic patients at the University Hospital of Montpellier (Montpellier, France). From their experience, they identified several problematic situations relating to drug allergy information. An allergology Ph.D. student and a technology company collaborated to design a solution for allergy information traceability.

This research work was led by an industrial Ph.D. student in information systems (hosted by the technology company) following to the different stages of an ADR (Sein et al., 2011), such

as the formulation of the problem, BIE, reflection and learning, and formalization of learning. The data was collected and analyzed by physicians and patients during the first two phases using qualitative methods. The final two steps helped formulate the learning that emerged from the ADR process (Figure 21 illustrates the research design).

The ADR team described above clarified the problem and solution during three face-to-face team meetings and multiple email exchanges. At the end of these exchanges, the current functioning of healthcare processes regarding drug allergies had been detailed by the allergists (See Figure 17).

We analyzed this process to identify problematic situations in terms of process weaknesses or shortcomings. Thus, we have grouped problematic situations concerning the different dimensions of information quality and then focused on the existing solution's weaknesses.

This problem formulation allowed us to start the phase of BIE performed in three cycles. The IS Ph.D. student modeled the solution and an IT developer of the technology company built the app. The ADR team also performed the intervention and evaluation concurrently at the University Hospital of Montpellier. Two interview rounds (respectively for mock-up and alpha version) were performed. The first round of mock-up evaluation was considered in the second cycle of the BIE cycle. The second round of alpha-version evaluation are used for further versions.

The evaluation data was collected using semi-structured interviews. 16 interviews were audiotaped and transcribed, lasting 25 minutes on average. The first authors inferred relevant themes using inductive thematic analysis, which is inspired by grounded theory (Corbin & Strauss, 1990; Sekimoto et al., 2006) and adapted by Gioia et al. (2013). All the interviews were coded by a first code closed to respondents' words. Next, a more general coding was performed according to the dimensions of information quality. The design principles have been deduced from the coding process, translated into design features, and implemented in the development of the artifact in a digital application.

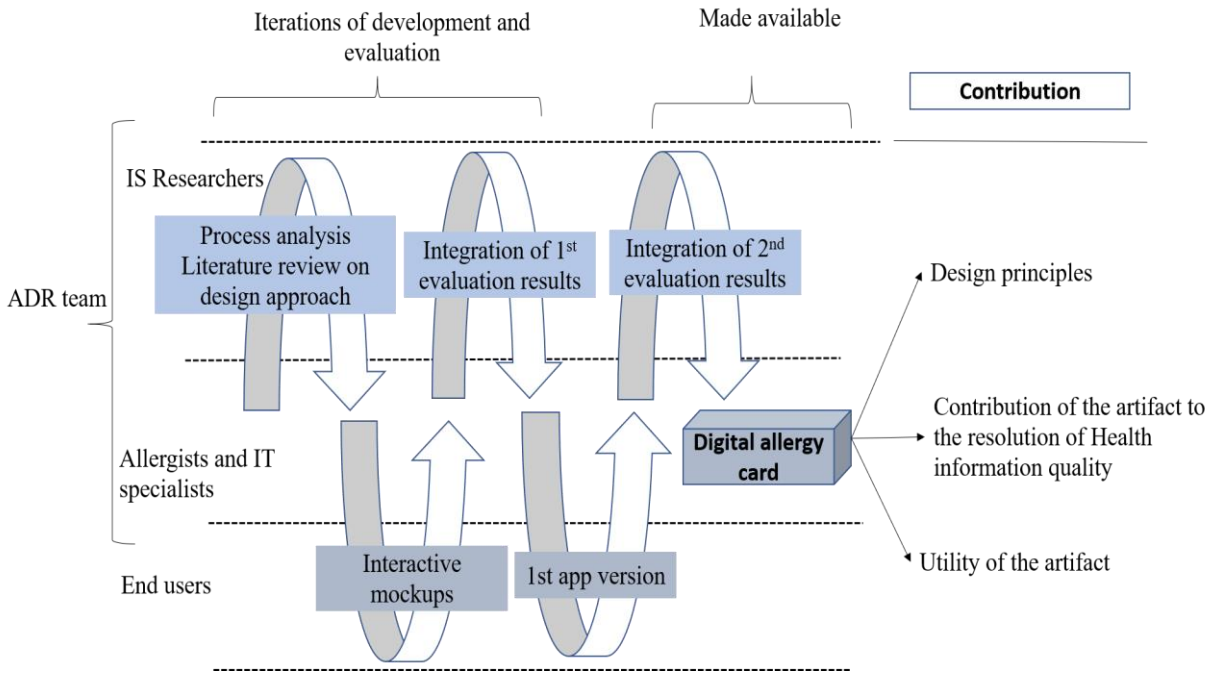


Figure 21. Action design research cycles

2.4 Application of action design research to the case of drug allergy information

This section presents our research process results. Gregor and Hevner (2013) assume that the results section can describe the design process.

2.4.1 Problem formulation

The formulation of the problem led us to identify the problem of allergy information quality. From the process described by allergists, we have identified the different manifestations of the problem according to the dimensions of the information quality presented in Table 13 below. The first column of Table 13 reports the different aspects of the allergy information quality problem we identified. The second column reports how each dimension occurs during allergy information. The third column reports the corresponding dimension of information quality.

Table 13. Identified problems and their manifestation

Manifestations in the process of drug allergy information	**Description**	**Information quality dimensions**

Patient or physician fails to report the allergy information	Ignorance of patient allergy	Availability
Storage of allergy information in EHRs Paper documents must be carried all the time Paper documents can be easily lost	Storage of allergy information in isolated systems Lack of interoperability between systems Information loss or inaccessibility	Accessibility
The allergy information is not tested	Self-reported information Confusion between self-reported and confirmed information	Accuracy
Several ways to report drug allergy information	The information is not organized	Structuring

The problems summarized in Table 13 above relate to drug allergy information quality that can hamper the decision-making process in terms of drug prescriptions and can lead to various consequences. First, the re-administration of risky drugs can lead to fatal anaphylactic reactions (Apter et al., 2004). Additionally, alternative medications may be less effective and cause antibiotic resistance (Golden et al., 2011). Thus, we argue that the cases of drug allergies as described above comprise an example of a class of problems that relates drug allergy information quality to health information quality in Sein's (2011) sense.

Among the existing solutions described in the process, we find that each one can solve the problem only partially. The paper format allows the patient to carry the information with him/her every time he/she has a medical appointment; this implies that, for each additional piece of information, a new document must be issued. The EHR report allows the information to be accessible only within the healthcare facility. To address this weakness, solutions for interoperability and/or centralization of health data have been developed. These solutions raise other issues, such as data security and privacy, as well as data structuring. More

generally, several solutions are proposed to address specific aspects of the information quality problem in health applications. Taken in isolation, these solutions respond to the problems they address, but we can identify that, by addressing one dimension of the information quality problem, other dimensions may be neglected or negative effects may be exerted on another dimension.

These solutions highlight the fact that the starting point is the problem to solve and the endpoint is the choice of a solution among the multiple possibilities. However, this approach, which the literature refers to as a function-based design approach (Chen et al., 2013; Maier & Fadel, 2009a, 2009b), favors a partial vision of the problem by neglecting certain aspects of the problem or the emergence of other problems during the design process (Brown & Blessing, 2005; Chen et al., 2013; Maier & Fadel, 2009a).

2.4.2 Building, intervention, and evaluation (BIE)

Having identified that the problem is the function-based design approach, we focus on an affordance-based design approach. The affordance-based design approach makes it possible to start from the desired solution collaborate with the users to deduce all the possibilities offered and desired (Brown & Blessing, 2005; Maier & Fadel, 2009a). This permits a much more global vision.

Affordance is defined in information systems as a possibility offered by an object or artifact (Pozzi et al., 2014a). Affordances, as opposed to functions, are characterized by complementarity, polarity, multiplicity, quality, and form dependence (Maier & Fadel, 2009a).

- Complementarity refers to the fact that the affordance is relative to both users and artifacts so that it cannot exist with respect to either subsystem in isolation.
- Polarity refers to affordances being either positive or negative depending on whether the potential behavior has beneficial or harmful consequences.
- Multiplicity refers to systems having multiple affordances. A health application, for example, affords information collection and storage.
- Quality refers to affordances being of varying quality depending upon how well the subsystems support the potential behavior.

- Form dependence refers to affordances depending on the physical structures of artifacts, unlike functions, which are form independent.

Despite the complexity of the health field described in the literature being a point of vigilance in the design of health applications, no study is interested in the affordance-based design approach to consider needs holistically and not individually or partially, as is currently done with a function-based approach.

To apply this solution to our case, we have identified the different subsystems that would be useful to consider as follows: (1) the artifact, i.e., the application we intend to design, (2) the existing healthcare practitioner system, very well known by physicians as the main, and sometimes the only, tool they use, and (3) the stakeholders made up of providers, patients, next of kin, regulators, and purveyors (Mantzana et al., 2007; Payton et al., 2011).

This affordance-based solution starts from the global view of the system being considered—i.e., the links between different subsystems—and then moves to the formulation of needs directly as affordances, which is simple since, according to the psychological point of view, people perceive the environment in terms of what said environment affords them (Gibson, 1979).

	Artifact	Actual HER	Patients	Physicians	Next of kin
Artifact		Information capture via interoperability	Information access	Information access	Information access
Actual EHR				Information access	
Patients	Information entry Grant access			Transmit information	

Physicians	Information entry Ask for access				
Next of kin				Transmit information	

Table 14. Subsets to consider for health information exchange

This affordance-based approach led us to identify the application's affordances by asking users for their perception of what a DAC application can afford to do. According to Table 14, in which we identified the subsystems and how they relate, we noted initial affordances for a DAC: information collection, information access, and secure sharing of information. These steps align line with the relational view of the affordance-based design approach (Maier & Fadel, 2009b), which makes it possible to identify the affordances between the users and the systems as well as the affordances within the different parts of the system.

The first cycle started with the design principles (DP) of information collection and user-controlled transparency.

DP1. Information collection: The health application should have features for patients and physicians to enter complete information for a clinical purpose.

DP2. User-controlled transparency: Patients and their next of kin and physicians should be able to access patient information that it is controlled by patients in the health application.

The first principle represents the affordance of information collection that addresses the dimensions of information availability and completeness. The second principle represents the affordances of information access and secure sharing that address the dimensions of information security and accessibility.

During this first cycle of BIE, researchers in information systems performed the building component, particularly the first author of this paper for the drafting of specifications, UML modeling of the solution, and the design of interactive models (wire frames). These different deliverables were discussed and improved during the intervention and evaluation, which comprised team meetings and formative evaluations (Venable et al., 2016) with six patients.

The first BIE cycle produced a supplementary principle—**DP3. Information structuring—** that helps distinguish the different statuses of drug allergy information (self-reported, confirmed, or ruled-out) and to classify information in a well-organized way so that patient might access them more easily.

During the second BIE cycle, we considered the three design principles mentioned above. The construction was carried out by an IT developer of the DAC and an industrial PhD student, who ensured that all the specifications discussed during the team meetings were considered in the development of the application and the outputs of the first BIE cycle. Therefore, we deduced two additional design principles from evaluation feedback: **DP4. Continuous evaluation of the information** and **DP5. Information understandability**

At the end of the first two cycles, the principles deduced (see Table 15) are input for the development of a beta version.

Table 15. Coding of the interviews and deduction of design principles

Verbatims	First code	General Code	DP
Patient 4: "In this kind of thing, I am completely … I find that it is good. It is good because we do not always have the memory. It is not a question of age. We have not always the memory of the dates of the facts, things like that. It goes into oblivion and then …"	Forgetting allergy information without a registration system and traceability system	Availability and completeness	Real-time information collection and editing
Patient 2: "After the doctor could correct, it can be interesting."	Interest in information corrected by the physician	Editing for accuracy	

Physician 1: “Usually, they tell you they are allergic to the Augmentin because they had belly pain or ... Well, often it is not proven. And after, I try to ask questions, to make up my own mind if it was a severe reaction or not.”	The information declared by the patients is not sufficient, and the physician tries to support the diagnosis by his interrogation	Accuracy	Continuous evaluation of the information
Patient 5: “My doctor saved it on my computer, but I think the information is not there. It was not accessible for the dentist, for other physicians.” Patient 3: “If it’s digital, it’s still faster. I think it is safer, remains to deal with the problem of confidentiality.” Patient 5: “What I find interesting for the future if you want to develop your application is to give access to hospitals, all hospitals in France. Because for me, this application is really useful in case of an accident.”	Allergy information is recorded in the isolated system of the physician or health facility A digital allergy card must deal with the confidentiality problem Allergy information should be accessible by all hospitals instead of individual physicians	Accessibility Privacy	User-controlled transparency and institutional transparency
Patient 4: “It was not difficult; it was that there were more things. But there were things I didn't	Some fields of the application are not	Understandability	Information understandability

understand”	sufficiently clear		
Patient 3: “It [digital allergy card] would have systematized things while it was there. I mean I said, and I was believed.” “…to be able to distinguish the allergic reaction from the skin thing that has nothing to do with it, I thought that was pretty good.”	A digital allergy card brings proof of what is said A digital allergy card distinguishes between the real allergic reaction and other adverse reactions	Accuracy and data organization	Information structuring

2.4.3 Reflection and learning

Based on what emerged from the BIE phase, more particularly from the evaluation in the context of use, we revised and completed the principles initially considered.

DP1*. Real-time information collection and editing (revised version of DP1): The health application should have features for patients, next of kin, and physicians to enter and edit health information as soon as possible so that the information in the application is complete and consistent for its clinical purpose.

DP2*. User-controlled transparency and institutional accessibility (revised version of DP2): Patients and their next of kin, physicians, and healthcare institutions must be able to access patient information in a way that is controlled by patients in the health application.

Additionally, three other principles have been added as follows:

DP3. Information structuring: The health application should have features that allow the organization of information according to its status (self-reported, confirmed, or ruled out) and chronology. The information should also be visible when the application is launched.

DP4. Continuous evaluation of the information: The health application should have features to edit the information status and alert for a reevaluation of the information.

DP5. Information understandability: The health application should contain comprehensible information for patients and physicians to enter or use quality health information.

At the end of this process, certain outputs had not been planned (see Table 16).

Principles	Consequences
DP1'. Real-time information collection and editing	Render the information available for further use as soon as that user is aware of the information (anticipated) A delayed information entry can hamper the completeness and even the availability of the information (unanticipated) Next of kin must be able to enter information and might grant access to the physician on behalf of the patient (unanticipated)
DP2'. User-controlled transparency and institutional accessibility	Facilitate the access of the information by different physicians and next of kin (anticipated) Need to grant access to hospitals rather than individual physicians (unanticipated)
DP3. Information structuring	Set information in a well-organized way so that accessibility and visibility will be improved (unanticipated)
DP4. Continuous evaluation of the information	Guarantee the accuracy of the information (anticipated) Alert for the reevaluation of the information after a certain period (unanticipated)
DP5. Information understandability	Guarantee that the stakeholders understand each other (anticipated) Anticipate the possibility of a physician correcting erroneous

	or incomplete information (unanticipated)

Table 16. Consequences of the building, intervention, and evaluation step

2.4.4 Formalization of the learning

In summary, at the core of the literature on drug allergies, there is the main theme of allergy information, which represents vital health information in the patient care process because it has direct impacts on patient safety, as mentioned above (Roehrs et al., 2017). Therefore, as an empirical example of a larger class of problems, health information quality, which the literature has often mentioned is associated with current problems of accessibility, traceability, and security (Cruz-Correia et al., 2013; Kohli & Tan, 2016), wed use an affordance-based approach to infer design principles applicable to any other type of health information because they have the same purpose in the care process and same constraints from legal and regulatory points of view.

This articulation of the class of problems, the class of solutions, and the design principles for this class directly satisfied ADR's generalization principle (Sein et al., 2011).

2.5 Discussion

This study aims to propose a solution to the problem of information quality during the design process of a health application. We used an ADR framework for this purpose.

The first phase of problem formulation allowed us to identify that the function-based design approach, which is used for the current health application design process, hampered the class of information quality problems that is visible in the case of drug allergy information. This effect occurred because this approach favors the resolution of a specific problem without considering the entire complex environment of the health field or the complex nature of the problem. We relied on the use of an affordance-based design approach during the BIE phase. The outcomes of this process are the artifact and deduced design principles.

We identified that a health application such as the DAC, which is the subject of this study, affords information collection, secure sharing, access, accuracy checks, and information storage. During the BIE phase, we considered the different characteristics of an affordance, such as complementarity, polarity, multiplicity, quality, and form dependence. This appraisal led us to consider simultaneously the whole system as well as the different interactions

between the subsets of the system. Therefore, we identified relevant subsets comprising the DAC, which is the resulting artifact, actual EHRs, and different stakeholders, who are patients, physicians, and next of kin (Mantzana et al., 2007; Payton et al., 2011). We further examined how each subset interacts with another so that the corresponding design features could encompass each specific aspect of the information quality problem consistently according to the complementarity nature of affordances that constraint to consider the same affordance for each subset of the system (Maier & Fadel, 2009a). This method also allowed us to prevent the potential negative effect of an affordance, capture all internal (within the technical system) and external (between the technical system and the users) affordances, and then find for all those affordances the right form. Indeed, one of the fundamental differences between functions and affordances is that, for one function, several types of artifacts can be imagined (Brown & Blessing, 2005; Chen et al., 2013), which moreover favors partial problem solving since it has the consequence of stopping the exploration process when the functions first defined find their satisfaction in the developed artifact. However, when we consider that user needs are often not very clear at the beginning but become clearer with time, the affordance-based approach seems more appropriate since, from a device, we tease out the different things that the user can do with it (Brown & Blessing, 2005; Chen et al., 2013), thus bringing a more global perspective. Indeed, designing the artifact from the users' point of view makes it possible to identify the flaws in the artifact at an early stage.

We deduced five design principles (or technological rules) from the BIE phase that were applied during the design process to solve the targeted problem of allergy information quality (Mandviwalla, 2015). We formulated the design principles according to Gregor et al. (2020). Therefore, this problem belongs to the more global category of health information quality, allowing us to generalize the design principles to this large category during the last two phases of the process.

In summary, we conducted two BIE cycles. The first cycle began with the principles of information collection and user-controlled transparency, making it possible to address the dimensions of availability, accessibility, and privacy of allergy information. Finally, three principles were added: continuous evaluation, information structuring, and information understandability. The application of these design principles during the BIE phases generated anticipated and unanticipated outcomes.

2.5.1 Deduced design principles

The initial principle related to **information collection** represents the entry of information in the application by users. We initially considered only the patients and the physician for this purpose, but the iterative evaluation process showed that the next of kin can also be involved in this action on behalf of the patient when he or she cannot enter the information personally. This consideration complements the role of a trusted-third party, which has often been limited to the transmission of information orally to the physician and a signature of consent when the patient is unconscious or a minor.

Later, we added a temporal consideration in the postponement of information to favor instantaneous capture to ensure that no part of the information is forgotten because of the delay and that the information is available as quickly as it is identified. This last consideration was also unanticipated, since a patient mentioned a risk of forgetting a part of bit of information during the delay between the reaction and the appointment with a physician.

The principle of **transparency** refers to the need to make information accessible and visible to the actors involved in patient care. In our specific case, we offer two access modes: (1) through interoperability between the application and existing systems (Dobrow et al., 2019) and (2) directly on the application for physicians who will have downloaded and created an account.

The health sector requirements and patient expectations include privacy constraints (Fernández-Alemán et al., 2013; Wiljer et al., 2008). Therefore, patients themselves should choose who should have access to their information by granting them access rights. Thus, we added user control. However, this control can be overridden in emergencies when an explicit agreement of the patient or a relative cannot be collected. The patients can grant access to the physician and a trusted third party, while a trusted third party can grant access to the physician.

An unanticipated outcome of this principle is that access by individual physicians can be limited, particularly when considering a patient’s stay in a hospital and his/her care by several physicians at the same time. Resultingly, the application should provide a way to grant access to the whole institution instead of an individual physician.

Capturing information open to all stakeholder profiles can have advantages, as explained above regarding the availability and completeness of the information. However, structuring the information is imperative to distinguishing between the information entered by the patients and that evaluated by the physicians. Thus, we propose the principle of **structuring and hierarchization of information**.

Indeed, drug allergies encompass one category of drug hypersensitivity reactions (DHR). DHRs may be classified into several other categories based on two main factors—the immunological nature of the reaction and its severity (Ferner & McGettigan, 2020). Depending on this classification, different therapeutic decisions may be made. The label of "drug allergy" itself corresponds to immune reactions, and, in the case of low severity and lack of proofs (no allergy work-up), a doctor may decide to override this label instead of opting for a less effective alternative drug (Ferner & McGettigan, 2020). Thus, the documentation of drug allergies must be sufficiently detailed in terms of the structuring of information to guarantee the safety of the patient.

Globally, the importance attached to the accuracy of health information requires **the continuous evaluation** of this information by doctors (Tang et al., 2006) to avoid confusion between validated information and that information reported by the patients. This principle also considers the chronological organization of the information, making it possible to provide details on the various changes in the information over time and possibly to alert physicians regarding the importance of a reevaluation.

Concerning the principle of **information understandability**, the involvement of patients in the care process through health application requires aspects of usability that involve both interfaces and content (Khajouei & Farahani, 2020). The content should be understandable so each actor can easily report and use the information in the application, and the interface should be easy to navigate so that each actor can retrieve the content. This principle is particularly important because it can prevent problems with the quality of information entered by patients using the application.

Furthermore, if patients understand the content of the application, they will be able to give the best information concerning their personal situation. Thus, we argue from the principle of information understandability that the more the content of the application will be understandable by users, the more precise the information entered will be.

An unanticipated outcome of this principle is that patients may unconsciously enter incorrect information; for example, the name of the drug that caused the reaction may be entered incorrectly. Therefore, we have provided a feature that allows the physician to correct the information while confirming or denying the self-reported information.

2.5.2 The resulting Digital Allergy Card

The first essential element of the result is the identification/authentication feature that uses services to verify each user's identity on the application. The second important element of the application is related to the allergy information process, from the user declaration to the status change.

A private blockchain is used to ensure robust traceability of the data. In summary, the multitude of stakeholders concerned in this DAC project relies on using a decentralized system, particularly considering the need for reliable allergy information for therapeutic decision making. Moreover, the solutions currently used to track allergy information are disparate; when centralized for better accessibility, they are dumped into the shared medical record in the form of a stack of PDFs, which has a certain accuracy but can slow down the physician's accessibility when the physician generally already has very little time to give to a patient. To improve the structuring, the abovementioned level of accuracy is met by robust traceability of the information through the blockchain (Nguewo Ngassam et al., 2020).

2.6 Contributions

We made both theoretical and practical contributions in this study that are exemplified by the design principles.

The design principles represent sufficient theoretical contributions according to Gregor and Hevner (2013), who discuss that the artifact and design principles are the main outcomes of DSR and ADR. More specifically, the design principles make it possible to fill the gap in our understanding of how to ensure the quality of health information during the design of health applications. Thus, we enriched the literature on health application design with the principles of information real-time capture, user-controlled transparency, hierarchization/information structuring, continuous evaluation, and information understandability to prevent health information quality issues. We do so by identifying that the problem could be predominantly resolved if the design approach addresses the problem holistically. Therefore, we demonstrate

that an affordance-based design approach could be an effective way to address the different sides of the health information quality problem.

As a practical implication, these design principles can be activated during the design processes of health applications. Indeed, each design principle should lead to the development of one or more application features.

2.7 Limitation and perspective

The main limitation of this study is that it only addresses one case, that of drug allergy information. However, the richness provided by other cases might make it possible to complete or validate the design principles that we have proposed, particularly because the affordances of health applications are related to the type of this health application (Jiang & Cameron, 2020). Therefore, further research is needed to complement and validate the proposed design principles. We suggest evaluating more cases using the ADR approach to solve the health information quality problem.

2.8 Concluding remarks

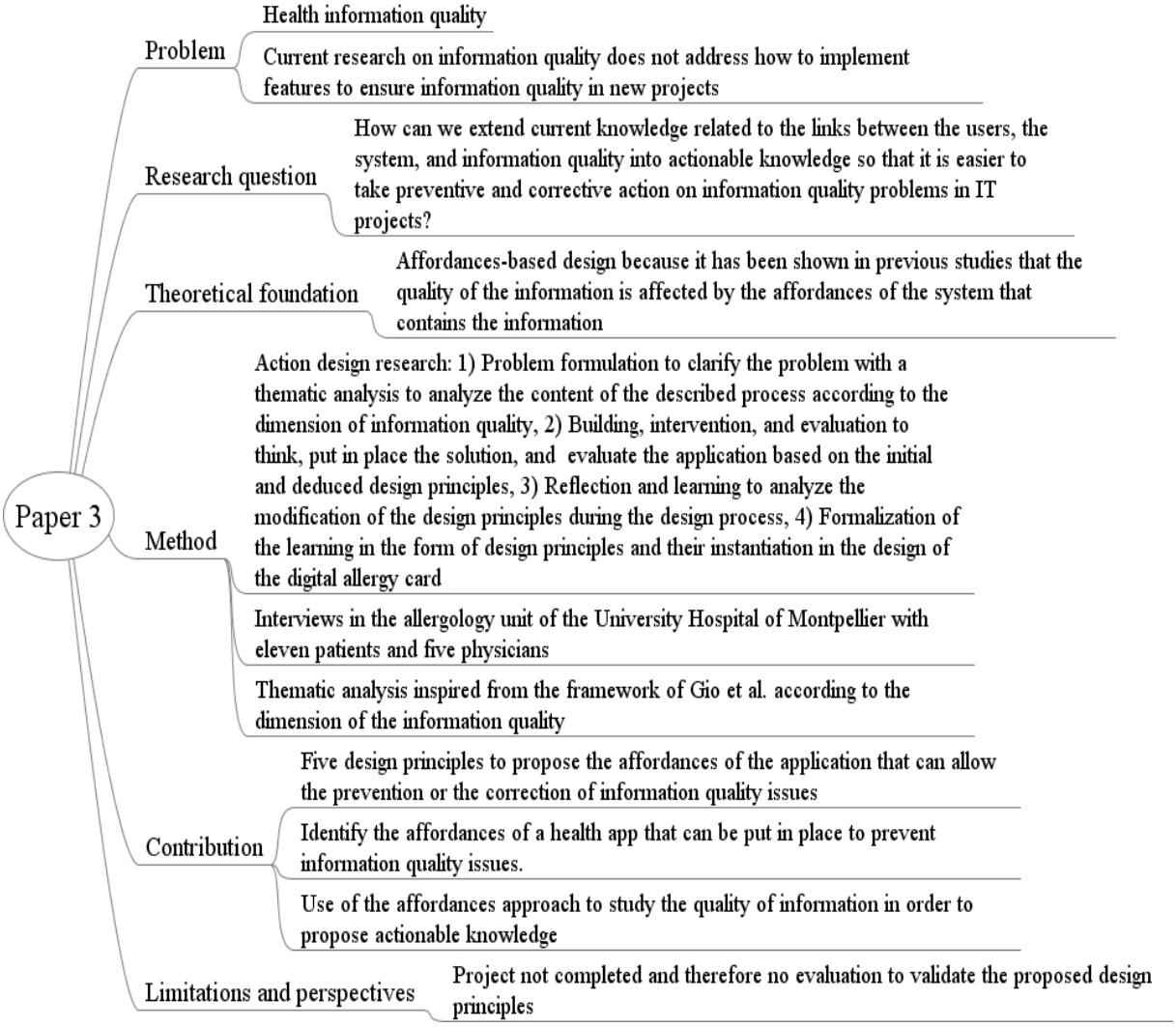
This study describes the process of solving the problem of health information quality during the design of a health application. We used an affordances-based design approach. We inferred five design principles that can improve the different dimensions of information quality. We applied these design principles during a case study we carried out related to drug allergy information quality. As a result, we obtained theoretical and practical contributions. Theoretically, our study specifically addresses health information quality in a holistic way, unlike other studies on health applications which solve separately and partially the dimensions of health information quality. Practically, the design principles deduced might be activated during design processes to make it possible to guarantee good-quality health information by acting on the different dimensions of the health information quality.

3. Synthesis and Articulation

We chose to integrate this article at this level of the thesis because it is related to a foundational part of the problem that initiated the project, i.e., the quality of the information.

We came to this conclusion during the formulation of the problem which could be summarized in different dimensions of information quality, including accessibility, availability, and structuring.

Figure 22. Synthesis of paper 3



One of the comments from the reviewers of the *BISE* journal was that the paper should have focused on one specific dimension of information quality. But one thing we noticed in our reflection is that the different dimensions are interdependent.

Paper 3 – affordance-based approach for e-health application to enhance information quality

This paper aligns with the thesis strategy in that it highlights evidence-based practice for information systems in the context of information quality.

While it is true that the literature for information quality is very dense in information systems, this study aims to propose actionable knowledge to actually implement information quality in a concrete case. For this purpose, we use the perspective of affordances and deduced five (5) design principles, which we have instantiated with design features.

One of the main limitations of this paper is that it does not offer generalizable knowledge. This is related to the small sample of people interviewed and to the fact that other evaluations were needed to validate the design principles. This could not be done due to the interruption of the project on which the paper is based.

We plan to continue this study when a new version of the application is available.

PAPER 4:

“Does the context matter for the adoption of a Personal Health Record: a field experiment design”

1. General information

This paper, the last of the thesis, is currently being finalized. A first version was presented as an emerging paper at the AMCIS conference in August 2021.

The objective of this paper is to revisit the data that emerged from paper 2 in order to test and validate the impact of contextual modalities on the adoption of PHRs.

Title	Does the context matters for the adoption of a Personal Health Record: a field experiment design
Authors	Rhode Ghislaine Nguewo Ngassam, Roxana Ologeanu-Taddei, Thao Bui Nguyen
Status	Work in progress
Access	-
Related communications	Americas Conference on Information Systems (AMCIS) 2021: "Examining the Moderating Effect of the Context of Use on the Intention to Use a Personal Health Record: the Case of a Digital Allergy Card"
Abstract	The number of PHRs has increased over the last few years. Consequently, literature has focused on the information privacy concerns of these PHRs. While many studies have highlighted that those concerns are a barrier to PHR adoption, no study has assessed the variability of those concerns according to other factors which may overcome them. Therefore, we propose an experiment design to measure the influence of the perceived benefits and privacy concerns in different situations on the intention to use a digital allergy card. We use the scenario method for a two-factor model. Scenarios are constructed according to the two-by-two composition between the context of mobility (traveler versus

	sedentary) and the level of severity of previous allergic reaction(s) (severe versus mild). We will enrich the literature on PHR adoption by the identification of contextual determinants which can influence the adoption of a digital allergy card.
Keywords	Adoption, context, privacy calculus, personal health records

2. Paper text

2.1Introduction

Over the past few years, Personal Health Records (PHRs) have expanded considerably with many e-health applications design and implementation projects (Ford et al., 2016). This growth is because PHRs have been assessed as an essential factor for avoiding medical errors, guaranteeing patient safety, reducing time loss, and reducing supplementary costs during the care journey (Roehrs et al., 2017). PHRs involve a variety of e-health mobile applications for chronic disease management and disease prevention. Nevertheless, their adoption issue remains a major concern (Vance et al., 2015).

Extensive studies on PHRs adoption issue identified several determinants that influence negatively or positively the behavior of patients and individuals (Laugesen & Hassanein, 2017; H. Li et al., 2014; Whetstone & Goldsmith, 2009). Most studies of PHR adoption are based on the Technology Acceptance Model (TAM) or Unified Theory for the Acceptance and Use of Technology (UTAUT) (Wu, 2016). The determinants are related to several categories such as personality traits, technology factors, information-related factors, environmental factors, and health conditions factors (Detmer et al., 2008).

Moreover, the existence and survival of a PHR is largely driven by making patients' personal health information available for access by physicians and other stakeholders(Payton et al., 2011). This access is limited by regulations and by individuals' privacy concerns.

Among the extensive studies of PHR adoption, several authors have found that privacy issues are a real barrier to PHR adoption (Roehrs et al., 2017). In addition, many studies and reports show that most people have serious anxiety about how their health information is obtained and used (Angst & Agarwal, 2009b; Zhang et al., 2018).

Privacy concerns arise when individuals are asked to provide health information to obtain the full benefits of using a PHR (H. Li et al., 2014). These concerns may even block the adoption of PHR (H. Li et al., 2014). Therefore, studying the drivers of PHR adoption and privacy concerns is becoming more important.

However, prior studies related to the adoption of PHRs and privacy concerns exhibit the following gap. While many studies have highlighted that privacy concerns are a barrier to PHR adoption, few studies has assessed the variability of those concerns according to other factors such as the benefits or the context which may override them (H. Li et al., 2014).

The privacy calculus perspective is increasingly used to examine the issue of information privacy and adoption of online services in many areas such as e-commerce sites or social networks (Jozani et al., 2020).

The "calculus behavior" is omnipresent in the adoption of technologies. Venkatesh had already identified this when he mentioned the fact that individuals may accept some difficulties if they see a clear benefit from using the technology in question (Gagnon et al., 2016). We stay in the same logic with the privacy calculus if we refer to the numerous authors who have mentioned the fact that 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. But all the medical care needs are not equivalent. For example some authors found that PHRs are particularly valuable for emergencies situations. 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, we propose an experiment design, based on the theory of privacy calculus.

The next sections present a background on PHR, the research model, the methodology, the expected results and the conclusion.

2.2 Personal health records

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 IT applications or entered by the doctor or the individual (Jiang & Cameron, 2020).

PHRs can integrate a variety of health information including the information about the daily routines of individuals or the clinical information, informing on physicians' reports about the health status of the individual (Norman Archer et al., 2011; Roehrs et al., 2017).These information are very insightful for the therapeutic decision making, guiding individuals in the self-monitoring of their health or helping individuals to change their life style.

Overall, this information is important for the safety of individuals (Sherer, 2014). Hence the importance of making health information available and accessible in a PHR. Indeed, the adoption and use of a PHR by an individual includes the authorization to disclose his or her health information in order to obtain all the benefits related to this PHR.

Most studies on the adoption of PHRs are either general (Whetstone & Goldsmith, 2009), specific to stand-alone or integrated PHRs (H. Li et al., 2014), or specific to chronic disease management (Laugesen & Hassanein, 2017). However, each type of health information has its own particularity, either in terms of immediate interest in the patient's care pathway or in terms of the sensitivity of this information (Zhang et al., 2018).

In this study, we are interested in drug allergy information, which 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).

The reason for our interest in drug allergy mobile applications also lies in the fact that this study is part of a project to design and develop a Digital Allergy Card (DAC) initiated by some allergists.

The DAC is then the instance of the large category of PHRs on which we will focus to realize this study.

2.3 Research model

In this section, we present the situational privacy calculus, the preliminary qualitative research, and then hypothesis development.

2.3.1 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). Five dimensions can be used to capture this trade-off, which are: performance, time, financial, psychological, social, and security.

Regarding the risks related to the use of online services that represent the negative part of the "calculus behavior", privacy represents the most popular risk according to several authors (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 or even mobile and web apps (Li et al., 2010).

Three concepts have been highlighted in the literature to measure privacy which are: perceived privacy risk, privacy control and privacy concerns (Jozani et al., 2020). Perceived privacy risk is defined as the possibility and severity of losing one's personal information as a result of the opportunistic behavior of other parties. Privacy control is the degree to which an individual believes to have control over the modification and dissemination of their personal information. 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 that we define as the trade-off of the consequences of information disclosure in a PHR, with privacy concerns as the main risk. These concerns, however, can be overcome by the benefits that the individual can derive from using the online service (Jozani et al., 2020).

The benefits of exposing personal information can be monetary, informational, personalization, social, enjoyment and efficiency (Jozani et al., 2020). In health, the benefits most often mentioned are related to health information, emotional support and safety (Buntin et al., 2011).

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 (H. Li et al., 2014).

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 (W. Li et al., 2014). The context or situation dependency has been demonstrated in several areas such as marketing, e-commerce, 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 are no studies that highlight the contexts that can mitigate or accentuate the impact of risks and benefits in the adoption of PHR. Therefore, we present in the next section a preliminary qualitative study that we conducted in order to identify moderating elements relevant to our model.

2.3.2 Preliminary qualitative study

As mentioned above, this study is part of a more global project of design and development of a DAC initiated by some allergists and conducted jointly with researchers in information systems and a partner in computer development. Within this framework, one of the objectives of this preliminary qualitative study was to highlight the levers and barriers to the adoption of

the DAC in addition to the usefulness that individuals could derive from it (paper under reviewing).

We collected data from 11 patients and 5 physicians through semi-structured interviews. 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.

To ensure consistency in data collection, the interviews were performed by both two PhD students, one in allergology and the other in information system management. These interviews, last 25 min each in average and were all recorded and transcribed.

Based on the transcribed interviews, relevant themes were inferred by the two PhD students 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 & Strauss, 1990). All interviews were assessed by a first code, close to the respondents' words. Then, a more general coding was performed. The resulting 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 and utility of the DAC emerged.

First, some patients identified the physician's advice, assistance or recommendation as an important lever for the adoption of the DAC. Thus, the fact that the physician recommends the use of a PHR may lead an individual to actually adopt it. Indeed, the decision to use an e-health application can come from either the individual, a relative, the government or the physician.

Second, a previous experience with a severe drug allergy reaction may also positively influence the adoption of a DAC to prevent possible subsequent reactions. This aspect highlights the value of the DAC for prevention and also the fact that the level of severity may have a stimulating effect on the intention to use.

In addition, being sedentary or travelling may also have a stimulating effect on the intention to use the DAC. Indeed, while some individuals who travel frequently saw the value of DAC

in making their information accessible wherever they go, the interviews show that the benefits of DAC are not very tangible for sedentary patients who always see the same physicians.

Based on these results, we chose to integrate the last two aspects, i.e. the level of severity of previous drug allergies (severe versus mild) and the mobility context (sedentary versus travelling) as moderators of our 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, theses variables are also relevant for PHR adoption topic in the sense that 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 behavior (Norman et al., 2005; Rogers, 1975).Thus a previous severe allergy may positively stimulate an individual to adopt a preventive or protective solution against a next potentially severe reaction.

Table 17. Table of codes

Verbatim	**General code**
“I might not have had the reflex to do that. If it came from the doctor, yes” **Patient 1**	Physician’s advice or recommendation
“I think that for me, since I have had a very serious allergic reaction, I think that this application is very useful” **Patient 9**	Previous experience with severe allergic reaction
“Yes, I've struggled so much with allergies and such that yes.” **Patient 11**	
“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 8**	Context of mobility
“and digital technology goes everywhere, it's fast. Right now I'm walking around with a medical file	

like that, a big file." **Patient 9**	
"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" P**atient 5**	
"I told you a little while ago, guidelines for each child. Also, what you have prescribed for us in case he has an allergic reaction". **Patient 1**	DAC benefits
"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**	
"If the database is dematerialized, the we can access it directly so it's interesting". **Patient 2**	
". . . If I make the parallel, for example, with regard to vaccinations or that we do not have the health record, etc. To prove that the we have had the vaccinations, it is not always easy or the we can lose the vaccination card; if the 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**	
"He contacts me directly, within the hour". **Doctor 1**	
"This app can guide me to inform differential diagnoses". **Doctor 2**	

2.3.3 Hypothesis development

In terms of benefits, as mentioned above, a PHR can have benefits in terms of information, i.e. improving the storage, structuring and completeness of information, facilitating accessibility and even ensuring the reliability and traceability of information (Vance et al., 2015). Then we have benefits that can be emotional when there are interactions allowing individuals to find comfort in relation to their situation for example (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 management of a disease (Vance et al., 2015). The variable perceived benefits 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., 2005; 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.

Several authors have found that users' perceived benefits on the intention to use an application (Whetstone & Goldsmith, 2009).

In the same way, the interviews of the preliminary study that we have previously presented show that the patients are very interested in the contributions of the application that is presented to them. In some speeches it is clear that the adoption is influenced by the benefits. For example, when asked if they would adopt the digital allergy card, one patient said, "yeah, if it actually provides access."

Therefore, we posit the following hypothesis:

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

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 tradeoff that the

individual perform before deciding on adopting a recommended behavior (Li et al., 2010). This tradeoff 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 (Hsieh et al., 2017). Meaning the more individuals have 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).

Many studies as mentioned above have measured the direct impact of benefits and privacy concerns on intention to use, however this impact can be mitigated or accentuated depending on the context of use. In this study, findings from the qualitative stage have shown that perceived benefits increases the intention to use a DAC. In contrast, privacy concerns seem to have a negative impact on this tendency.

Therefore, we formulate the second hypothesis as follow:

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

Based on the preliminary analysis, we have identified two potential factors that might explain the impact of perceived benefits and privacy concerns on the intention to use a DAC. Firstly, we have considered the individual context of mobility. Indeed, 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 is traveling (Saultz, 2003). We, therefore, distinguish between individuals who are traveling and individuals who are sedentary. In the context of e-health applications these categories are mutually exclusive. In the case of sedentary individuals, the need for the e-health application to facilitate the ubiquity of health information seems less important than in the other case where individuals have to consult different doctors in different hospitals. This argument is illustrated by the interviews of some patients who say that because they are

used to travel or to move, then the DAC is a more useful for them (See the context of mobility in the Table 17). Moreover, it would seem that traveling or moving a lot increases the benefits and interest of adopting the DAC.

For this reason, we posit that:

H3a: A travelling lifestyle accentuates the impact of perceived benefits on the intention to use a DAC more than a sedentary lifestyle.

Secondly, we have identified the perceived severity of the previous allergic reactions as a potential factor that can also accentuate the impact of the perceived benefits on the intention to use a DAC . Patients who have had a last severe allergic reaction are more likely to engage in protective behaviors to prevent further reactions, according to several authors who have worked on the protection motivation theory (PMT) (Norman et al., 2005). This is also clear from interviews with few patients who mentioned that they find a greater interest in adopting DAC in view of past experiences with serious drug allergy reactions. One of the elements that drew our attention in the speeches of these patients, beyond the fact that they have had reactions to drugs in the past, is the characteristics they give to their experiences. For example, one spoke of "very serious allergic reaction" Patient 9 and the other said "I have struggled so much with allergies" Patient 11.

Because of their allergy, they saw more value in adopting the tool. As mentioned above, the setting in which we conducted the interviews was an allergy unit where the patients we interviewed came for testing to confirm the existence of an allergy to a specific drug to which they had reacted. In recounting their experience, we noticed the indifference of some patients who had had less severe reactions to adopt or not adopt the tool compared to those who had had severe reactions. Indeed, this was evident in the speeches like one who said: "...frankly I wouldn't mind it being on my phone, it's a plus anyway."

Therefore, we hypothesize that this variable may accentuate the perceived benefits associated with the use of the application. We distinguish between the level severe and mild and we posit that:

H3b: A previous severe reaction mitigates the impact of perceived benefits on intention to use more than a previous experience with a mild allergy reaction.

Another interesting element that emerged from the interviews was the scarcity of the issue of privacy in the discourses. This may have several causes. First, it could be that the trusting environment in which the interviews were conducted (i.e., in the presence of the physicians) meant that the patients did not immediately raise the issue. In the literature, this explanation may be related to the trust that patients have in doctors to manage their health (van Velsen et al., 2017). One patient commented in this sense: "I might not have had the reflex to do that. If it came from the doctor, yes" Patient 1. Another possible explanation that is also supported by the literature is that the benefits of using the digital allergy card masked the risks. This corresponds to the postulate of the privacy calculus theory that we use in this work. Indeed, according to the privacy calculus, the greater the benefits related to the use of a technology the less important the risks are in the decision to use this technology (Beke et al., 2021; Jozani et al., 2020; Sheng et al., 2008). Another way of understanding it would be to say that the greater the perceived benefits, the greater their impact on the intention to use and the lesser the impact of risks on the intention to use the technology. Thus, anything that tends to increase the impact of perceived benefits on intention to use would mitigate the impact of privacy concerns on intention to use. And conversely, anything that tends to mitigate the impact of perceived benefits on the intention to use would accentuate the impact of privacy concerns on the intention to use.

As we have seen above, a travelling lifestyle tends to accentuate the impact of perceived benefits on the intention to use. Therefore, this accentuating effect on benefits would tend to mitigate the impact of privacy concerns on intention to use the DAC. So we posit that:

H4a: Sedentary lifestyle accentuates the impact of privacy concerns on the intention to use a DAC more than a travelling lifestyle.

Similarly, previous experience with severe allergies that accentuates the interest of using DAC for patients would also have the effect of masking privacy concerns and decreasing their impact on the intention to use. Thus, we formulate the following hypothesis:

H4b: A previous severe reaction mitigates the impact of privacy concerns on intention to use more than a previous experience with a moderate allergy reaction.

We include as control variables: 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 app (Jozani et al., 2020).

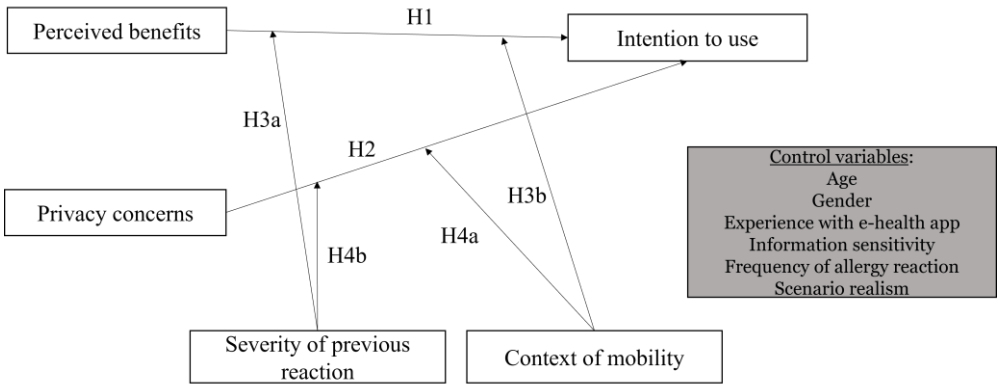


Figure 23. Research model

2.4Methodology

In this research, we examine and assess six hypotheses to explain the intention to adopt a PHR.

We propose to use an experimental design with the scenario-based method because it allows for manipulating variables and testing causal relationships. In this study, we employed a 2 (severe versus mild)X 2 (sedentary versus traveler)factorial design (see Figure 2).

Scenarios are narratives of events that put individuals in a certain situation to observe their reaction and predict their behavior (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 behavior of individuals according to the values of the manipulated items. In the specific case of our study, the scenario method would make it possible to include in the study even 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 scenarios are built as a written story. The severity of previous allergic reaction is constructed from the measurement scale developed and used by clinicians. Therefore, we plan to validate first these scenarios by allergists before carrying out the pre-tests with individuals to see if their perception of severity is the same. We use the different recognized 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 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 (4) scenarios that we will present to 4 groups of 50 individuals each. Therefore, we will collect data from approximately 200 patients in a university hospital in France. We assume a medium effect size (f=0.25), with a power of 0.80 at alpha equals 0.05 significance level (Cohen, 1988).

	Traveler	Sedentary
Severe	I	II
Mild	III	IV

Figure 24. Research design

2.5Expected results

Our contribution will be theoretical, practical and methodological.

By conducting this two-factor experiment anchored on the privacy calculus theory, we aim to contribute to the research by extending the privacy calculus theory for the adoption of PHRs

in different situations regarding the level of severity of previous allergy reactions and the mobility context of individuals.

On the practical level, we aim to identify the contexts in which the intention to use a DAC is more important; which will even allow the designers of this type of applications to better read their market and adapt the service according to the contexts.

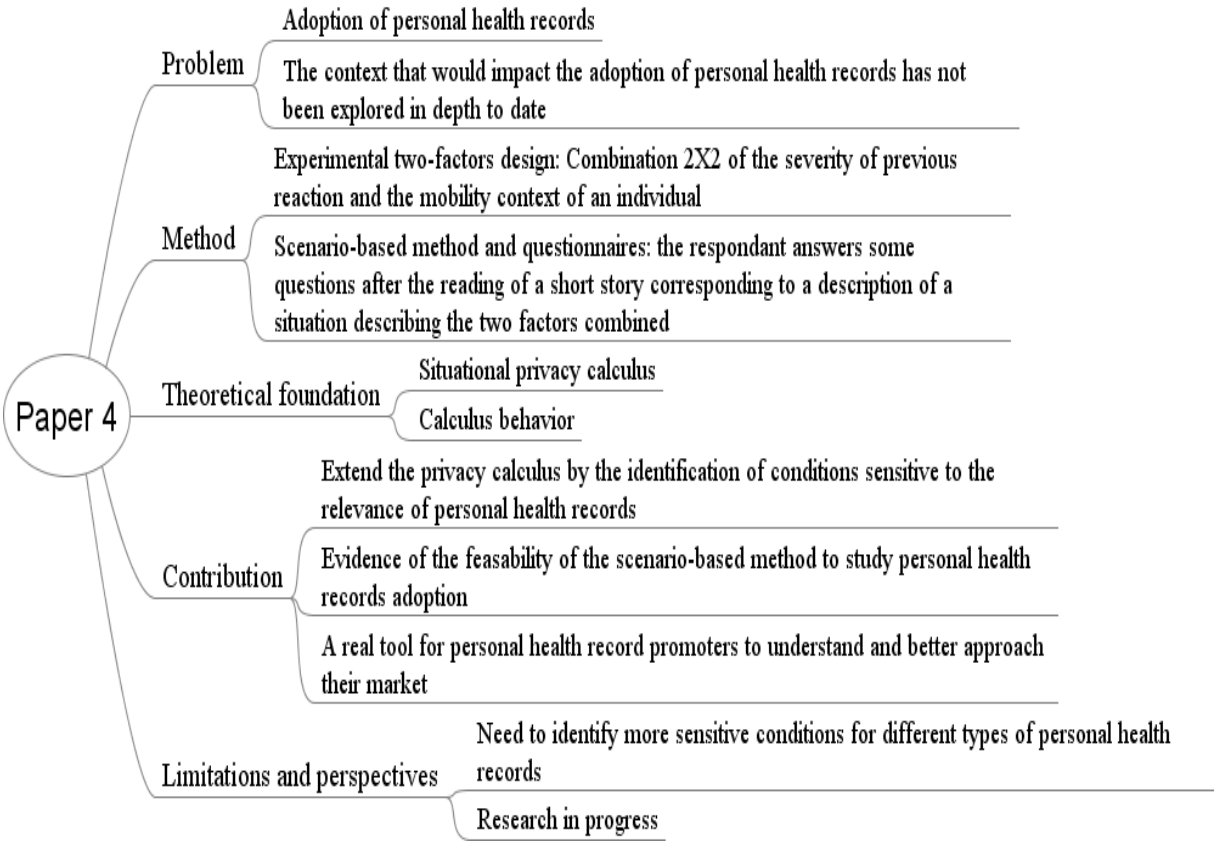
Methodologically, we want to provide empirical evidence of the feasibility of the scenario method in the field of PHR adoption.

2.6Conclusion

This paper develops a two-factor model anchored in privacy calculus theory to measure the change in privacy concerns versus benefits and context related to the severity of previous allergies and mobility context. We use the scenario method based on a two-by-two composition of moderating variables (severity of previous drug allergies, mobility context).We expect to contribute to the literature on privacy calculus in the field of PHRs adoption.

3. Synthesis and articulation

Figure 25. Synthesis of the paper 4



General discussion

Throughout our research, we observed that existing studies of PHRs were not sufficient to improve specific situations in the field by better capturing user needs and translating them into application features; better understanding the adoption problem and proposing actionable solutions; and, finally, guiding project promoters in the design of PHRs to ensure that information quality issues can be addressed effectively.

1. Synthesis of the papers and contributions

Starting with a real-life situation in the field of drug allergies, we launched a research journey into the problem formulation and user perceptions analysis and delved into the issues of adoption and information quality. Our research approach, which is mainly based on the methodological framework of action design research, is in line with our research logic inspired by the evidence-based practice for information systems. Our contribution to the thesis is mainly in the research propositions and design principles we have brought. We describe in the following scheme all the thinking paths that have led us to reach this point.

1.1 Contribution for research

To answer our general research question about what needs to be considered to develop a user-responsive PHR and to facilitate its adoption, we have four papers that answer a question specific to each and contribute to the general research question. In the first paper, we show a typical case of a technology, the blockchain, which seeks the problem it can address. This involves clarifying the need and preferences in the context where the technology is to be integrated. The other papers further clarify the needs grouped in two main challenges of PHRs: adoption and information quality. We detail the contribution of each paper in the subsections below.

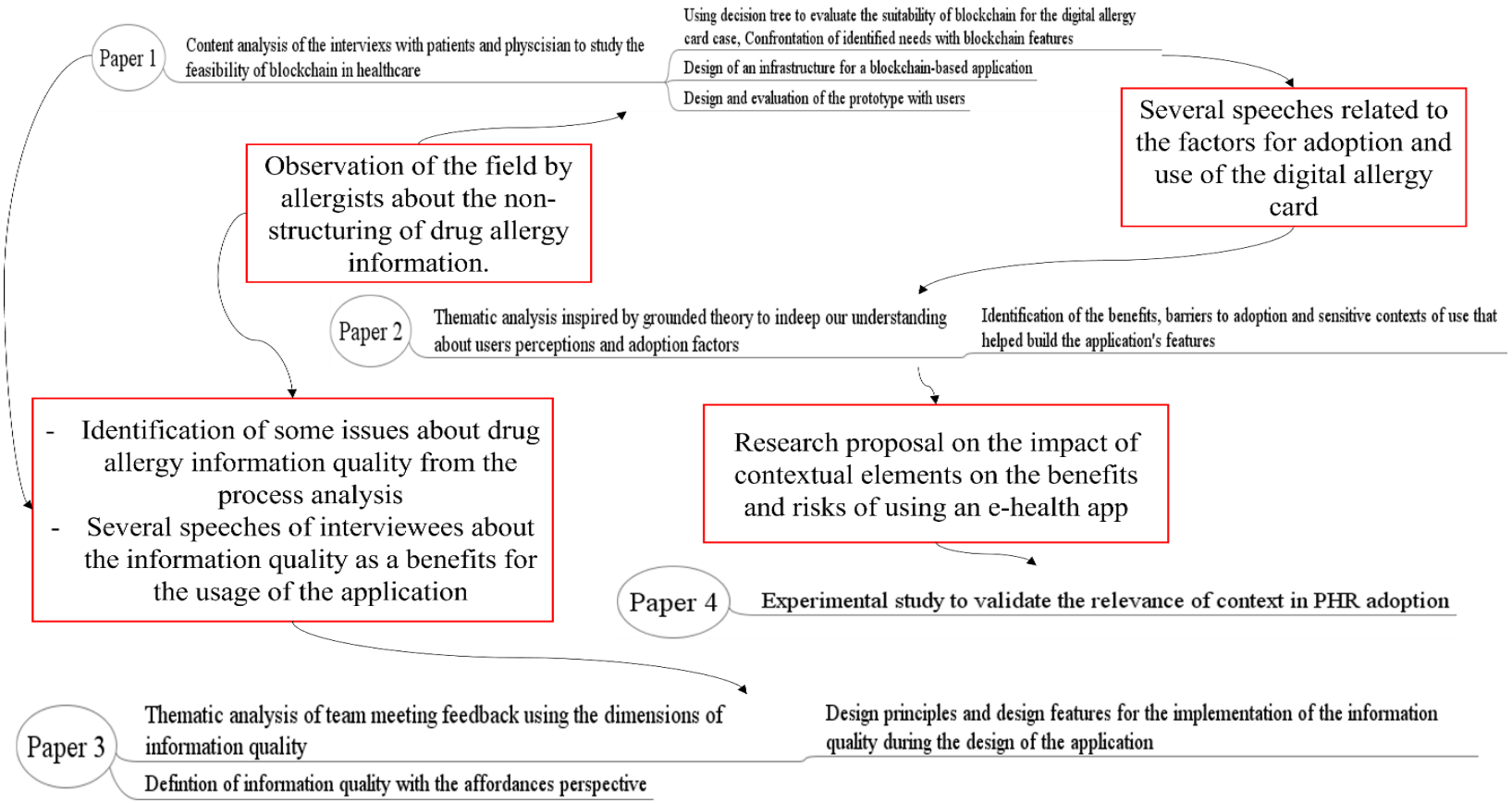


Figure 26. Synthesis of the papers

1.1.1 Blockchain in healthcare

Our reflection started with the consideration of the problem identified by allergists as a good use case for the integration of blockchain in healthcare. Starting from there, we initiated a study to analyze the identified needs and the features of a private blockchain. We conducted this analysis firstly with a 10-step decision process to test the relevance of the blockchain (Pedersen et al., 2019), and then we codified the identified need according to the main characteristics of the blockchain technology (Zubaydi et al., 2019).

Subsequently, we initiated the design of an app to track drug allergies based on the blockchain. In doing so, the description of the process related to the tracking of allergy information was described, and from there we imagined a target process that led to the modeling of the application and the development of the first prototype. During evaluation with the users, we tried again to highlight the elements that could correspond to the features of the blockchain. Indeed, we found that the best way to analyze the relevance of blockchain was not to ask the individuals directly, for they often don't know what blockchain is and its related benefits. A good way to analyze the relevance of blockchain could be this correspondence between its needs the features. We have observed in the literature that most of the studies concerning blockchain in healthcare are done by startups, big companies, or governments (Balasubramanian et al., 2021).

Applying blockchain in healthcare presents the following characteristics: first, ill-defined or unknown needs in a complex environment like healthcare that involves various stakeholders and non-standardized processes; secondly, a technology, the blockchain, whose features are not well known by the actors. In this type of situation, some authors suggest that, for existing solutions, we look for the problems they can address (Lomi & Harrison, 2012). The application of blockchain in healthcare seems to follow this logic because practitioners and researchers are proceeding in the same way as previously stated, i.e., they are looking for which aspects of healthcare use cases can correspond to the known features of blockchain—these features having been revealed with other applications of blockchain, such as cryptocurrencies.

Existing studies related to blockchain in healthcare follow this logic when they cite potentially relevant use cases for applying blockchain in healthcare. However, these studies

remain general and do not necessarily take into account the specifics of real cases in terms of needs, resources, and actors.

Our study aims to overcome these limitations by taking a real case concerning drug allergies. In doing so, we contribute to the research by identifying some specificities of the healthcare field eligible for blockchain application. Moreover, the illustration of the relevance of blockchain by a specific case also allows us to detect certain aspects we could not identify with a general approach—for example, how to ensure the blockchain once implemented for the access and management of nodes.

In the process of clarifying the requirements for blockchain feasibility analysis, several challenges were brought to light regarding mobile health applications. These comprise the challenges that have been the subject of reflections in the next papers. These are adoption and quality of information.

Each of these topics has been widely studied in information systems. But one of the main limitations observed in both cases is the fact that it is not easy to develop a practical guide on how to prevent problems related to adoption or information quality in e-health application design projects.

1.1.2 Facilitate the adoption of a PHR

One of the objectives of information systems research is strongly linked to applicability in practical projects (Aken, 2004). This implies that researchers should be able to popularize the results so that practitioners can have access to them. These results should also be easily usable or actionable in real cases. It is in this logic that researchers in design sciences and those who evoke the need for evidence-based practice for information systems are aligned.

Paper 2 of our thesis also follows this logic with regard to adoption. We started from the observation that the traditional models that allow us to study adoption, such as TAM or UTAUT—to mention only the most popular ones—do not allow us to really take into account the antecedents of adoption, i.e., the design (Benbasat & Barki, 2007). The knowledge gained from them remains very general (Benbasat & Barki, 2007). For example, when these models talk about benefits or ease of use, it is difficult for the practitioner to realize which elements of the system to develop to actually make it useful or ensure ease of use. One way of

acquiring this kind of knowledge is through action research, which is interventionist and coupled with design sciences. This combination creates actionable knowledge during the design and evaluation of artifacts.

Our research question for paper 2 was: What are the user perceptions of DAC, and how can we incorporate them into the application to facilitate adoption? During this study, we used thematic analysis to extract relevant themes from the interviewees' responses. First, we extracted the content and benefits of the digital allergy card that were related to specific features already on the prototype or that we added later. Secondly, we identified the contextual elements that could influence the adoption of this application, which allowed us to make research proposals that could be tested in future studies. These research proposals were the starting point for our reflections on the last paper, which is still in progress.

This study is not a call to stop studies such as TAM, because they have their advantages, including rigor and ease of generalization. Rather, Benbasat and Barki (2007) suggest to change the way people conduct adoption studies by focusing on different antecedents (design) and consequences (adaptation and learning behaviors) of IT adoption and use. More concretely, they suggest that IT adoption studies should look more at IT characteristics that influence adoption model constructs, such as perceived usefulness and perceived ease of use.

In the same sense, several authors have highlighted some of the limitations of TAM models in capturing the depth of the entire decision-making process. The design phase is important to take into account in this process because it is at this level that decisions are made by the designer to provide the elements that will influence the desire to make the decision to adopt a technology (Bagozzi, 2007).

Apart from the knowledge directly applicable through the features of the application, our study has also highlighted that there are some contexts more sensitive to the use of PHRs than others. Even if this information appears in the literature, the issue has often been treated in a global way. These, however, are the actual contexts experienced by individuals. When the literature mentions that emergency contexts are more conducive to the use of certain mobile applications, it is still necessary to empirically identify these contexts. Doing so could, for example, allow mobile application developers to adjust their market strategy by offering several services based around different contexts.

This element also extends the traditional adoption models by adding the issue of contextual variability. To ensure the validity of what we have noted in the reflections on paper 2, we propose in paper 4 an experimental study to test the variability of adoption behaviors using the privacy calculus theory. This study brings a touch of rigor to our work. Indeed, it is this rigor that is often missing in design sciences studies and that prevents the generalizability of the results (Mentzer, 2008).

Our latest study on adoption also uses a theoretical framework that we enrich by bringing the aspect of empirical context to bear.

1.1.3 Affordances and information quality

Among the benefits linked to the use of PHRs, the quality of health information occupies a primary place since the different dimensions of information quality condition everything else.

In fact, an individual's entire healthcare process involves decisions made by the physician, the individual, his or her family, or, in some cases, the government. For decision-making to have positive effects for the individual, it must be based on quality information, because information is the raw material of all decision-making. This principle is not only relevant to health but to all areas of an individual's or organization's life. In health, the quality of information is all the more sensitive because it affects the safety of the individual.

The quality of information is measured according to several dimensions, including availability, completeness, accessibility, accuracy, relevance, timeliness, etc. The history of the evolution of digital health applications allows us to see that the objective behind them was to improve these different aspects. Indeed, transitioning away from paper systems and manual back-up systems, we now have more sophisticated systems that allow us to optimize the traceability and quality of information throughout the individual's care.

This undoubtedly explains the great interest of researchers and practitioners in addressing this issue. It is from this same logic that our research question in paper 3 stems. But, unlike previous work, we use the lens of affordances to propose design principles to prevent information quality problems when designing health applications.

The particularity of this approach is that it allows the emergence of actionable knowledge in concrete cases of design and development of health applications.

Our reflection shows that the dimensions of information quality must be analyzed individually and as a group because they are interdependent.

The affordance approach also allowed us to understand that the quality of the information is not static but results from a meaningful interaction of the individual with the application or a good interaction between different subsystems of the application. Specifically, we believe the affordances approach allows us to answer our research question.

1.2 Methodological contribution

This thesis uses several methodological approaches to answer the different research questions.

First, the ADR methodology contains four stages. The first stage is problem formulation; the second is building, intervention, and evaluation; the third is the reflection and learning; and the last is related to the formalization of learning. We used the anatomy of design principles proposed by Gregor, Kruse, and Seidel (2020) to formulate design principles and the thematic analysis in the evaluation rounds, drawing from Gioa, Corley, and Hamilton (2013).

The evaluation feedback was used to improve the artifact iteratively as well as to highlight elements related to the adoption issue that was later used in the adoption model tested through an experimental study with the scenario-based methodology (Camponovo et al., 2004; Sheng et al., 2008).

The combination of these methods adds to the rigor versus relevance debate of our research work. Indeed, while ADR ensures that the practical problem is answered in a relevant way, the experimental method complements it to test some of the impact of empirical contextual factors on PHR adoption.

This combination joins the bi-paradigm of information systems research as well as the call of several authors to use these paradigms in a complementary way (Hevner et al., 2004). This complementarity is illustrated in our work by the fact that we start from an ADR process for an experimental study based on the ADR results.

1.3 Transferability of academic knowledge to the e-health field

The need for quality health information is justified in all decision-making situations, especially in sensitive cases such as the management of the Covid-19 crisis. This is a concrete illustration of a context in which it is vital to have quick access to all information to effectively manage the patient. The case of the digital allergy card is also very well justified in this context since hospitals throughout the crisis have had to manage large crowds for hospitalizations, with vaccination centers similarly struggling.

On a practical level, our thesis contributes to the case of drug allergies and more generally to the optimization of the health information process. The knowledge gained from this research provides clear contributions to PHR project sponsors and to the evidence-based information system for practice in general.

1.3.1 Managerial contributions

We suggest throughout our thesis that the treatment of problems encountered in the field should be done in such a way that we can emerge with actionable knowledge. The proof of actionability is given through the fact that we directly apply the different knowledge in the project of design, development and evaluation of the digital allergy card as an instance of PHR.

Moreover, the methodological framework of action design research (ADR) allows us to highlight design principles or research proposals that can be used beyond the framework of our case.

Regarding blockchain in health, we believe that the analysis approach and the application architecture we proposed could be very useful for other e-health projects integrating blockchain. Indeed, our case study allows us to highlight the functional specifications of the field that could be conducive to the integration of blockchain for a given project.

With respect to adoption, we follow Benbasat and Barki's suggestion to link to antecedents to adoption such as the design phase (2007). For the case of the digital allergy card, we identify the benefits, barriers and contexts sensitive to the use of the application by showing through a real case how to implement this in the application features.

With respect to information quality, we propose features of health applications corresponding to the dimensions of information quality individually and according to the interactions between them. This would be useful for PHR developers to be able to integrate them in the applications to prevent information quality problems.

1.3.2 Contribution to the evidence-based practice for information

As the amount of e-health research continues to grow, practitioners are constantly asking for the ability to draw on research findings for action. One example that illustrates this is the funding of numerous research endeavors by governments to set up health blockchain projects.

However, the "transferability" of this academic knowledge to the field, i.e., the concrete application of data from the literature for decision-making by those who practice IS, develop them, choose them, and implement them, is not obvious.

In a very recent article, Wainwright et al. criticize IS research for being undertaken primarily "by IS researchers for other IS researchers" and, as a result, not being fully utilized by those "who practice" IS, i.e., those who choose to adopt an IS or are involved in implementing it (Wainwright et al., 2018). The authors argue the value of refocusing IS researchers' (and practitioners') efforts to develop evidence-based databases of IS research so that practices related to the use of ISs can be more systematically informed, developed, improved, and supported (Wainwright et al., 2018). As abundant as information system knowledge is, it remains inaccessible to practitioners. Subsequently, this knowledge is of little use to those implementing IS in their organizations and looking to inform their decision-making; they are more likely to take advice from an internal expert or external consultant than to turn to the academic literature for empirical evidence of what has—or has not—worked in situations similar to their own (Baskerville & Myers, 2002). Baskerville & Myers (2002) called for IS researchers to lead actions rather than analyze ex-post as they currently do.

Jabagi et al. define practical contributions as relevant when they present arguments that are persuasive (actionable) and easily digestible by field actors (applicable and accessible) (Jabagi et al., 2016a), with knowledge that can "enable field actors to take action" (Majchrzak et al., 2016) to solve field problems. The research work must not only participate in the description and understanding of a phenomenon related to the use of an ES but also

"generate useful knowledge with the goal of building a better future" (Markus & Mentzer, 2014).

Wainwright et al. therefore advocate for new perspectives on IS research aimed at an organization of knowledge that allows for the emergence of "evidence-based practice" (Wainwright et al., 2018). Wainwright et al. use the analogy of evidence-based medicine (EBM), defined as an approach that integrates best practices from clinical research evidence (methodologically rigorous) with professional expertise and patient context (individual preferences, concerns, expectations, and values) (Sackett et al., 1996). The concept of evidence-based practice has also been adopted and adapted as needed in other disciplines, including software engineering (Kitchenham et al., 2004), management (Pfeffer & Sutton, 2006), social policy (Pawson, 2006), and education (Petty, 2009).

We believe that action design research can be one of the cornerstones of this "evidence-based practice for IS," permitting the direct application of academic data by confronting it with the reality of the field and thus the genesis of new knowledge while designing IT artifacts. Indeed, ADR involves both the action research and the design sciences research, making it perfectly adapted to the study of technology in its human context and dedicated to developing useful knowledge for both research and practice (Baskerville & Wood-Harper, 1996). The action research is distinguished by its interventionist approach. The objective of our action research design was to propose concrete and useful solutions for the development of PHR. We believe that the knowledge deduced from this approach can be easily reproduced in other e-health projects.

2. Limitations and research perspectives

The main limitation of our research work is the fact that we were diverted from the initial objective of exploring several use cases of blockchain in healthcare. As a result, we collected very little data, and we unfortunately only present one use case, which is related to the traceability of allergy information.

First of all, the suspension of the project due to the financial issues caused the collection of minimal data. If the project had continued, additional evaluations would have been conducted on subsequent versions of the application, and even further analysis in real use situations could have helped to flesh out and validate our research proposals and design principles. This

may also limit the significance of the results. To remedy this, we set up study 4 of our paper, which is an experimental study allowing us to validate the results we obtained with the qualitative methods deployed—in particular, the importance of the context of use in the adoption of PHRs.

In the same sense, the fact that the research involves only one case could be a source of bias related to the reproducibility of PHRs, the unique case of our study. We suggest that future studies should privilege a comparative approach on several instances of PHRs.

These limitations we mentioned are all linked to the fact that our thesis was seriously affected by the hazards of the project we had set up and by the fact that other projects that could have allowed us to compare could not be started. Even though, through the study in paper 4, we aimed to collect more data and bring a touch of significance to our results, the main limitation related to the initial objective of the thesis remains.

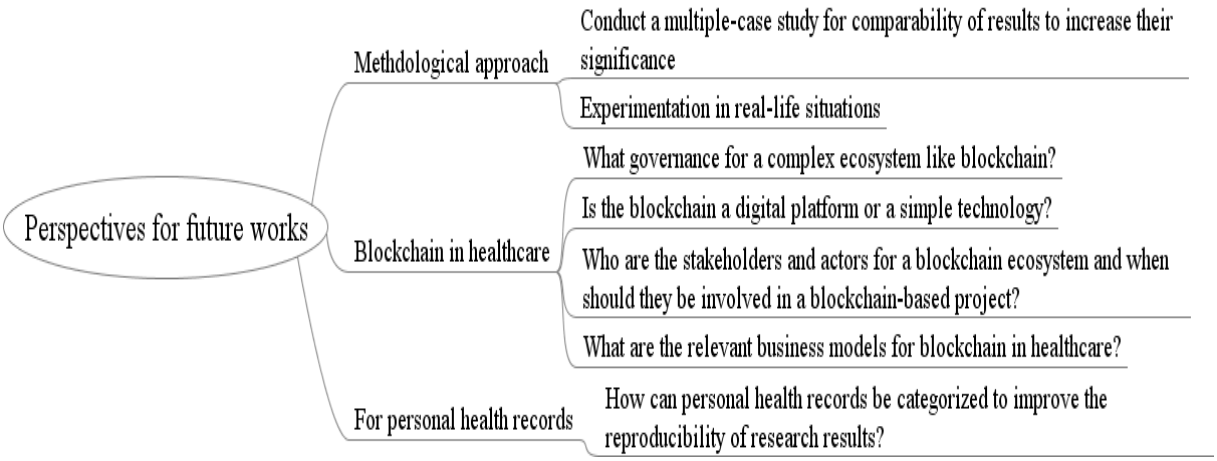
From a research perspective, we believe that researchers should focus on multi-case study and consider blockchain as an IT-platform. Indeed, we think, with hindsight, that the vision of the integration of blockchain in health is not limited to the implementation of a technology, its complexity related to the different stakeholders, the structure, and the multiple applications that can be grafted to it make us think more of an IT platform that is defined as "general-purpose technology that enables a family of applications and related business opportunities" (Fichman, 2004). Digital platforms contain the following characteristics: "polycentric, multi-nodal, multi-sector, multi-level, multi-actor, multi-logic, multi-media, [a] multi-practice place characterized by complexity, dynamism, uncertainty[,] and ambiguity in which a wide range of actors are engaged in public value creation and do so in shifting configurations" (Thompson & Venters, 2021).

A vision that does not involve this complexity could cause the project to fail or slow down, as was somewhat the case with the digital allergy card that involves not only end users but also other stakeholders involved in the use of the blockchain-based application. This complexity also leads to other challenges, such as adoption or the business model that corresponds to this type of ecosystem.

It is in this context that I will continue: the context of a postdoc on the initial theme of this work related to the use cases of blockchain in healthcare. Specifically, we will look at the governance of a blockchain ecosystem.

We will explore two cases, that of the digital allergy card that we started during the thesis and that of the traceability of clinical consents that was launched a few months ago thanks to funding from the region. These two cases represent two very important parts of health information that entail differing challenges. Firstly, allergy information is linked to clinical data, and any study on this subject involves a clinical study to evaluate the clinical effectiveness of the proposed service. Consent data, on the other hand, does not directly affect the health of the individual but rather is part of the supporting processes of the patient's healthcare pathway.

Figure 27. Research perspectives



In the case of the digital allergy card, the project will be relaunched by the allergists, who will also launch the clinical study. The idea here will be to choose a blockchain solution to be integrated, to follow the constitution of the ecosystem, and to carry out various interviews and observations to better understand how the governance of such an ecosystem works. For the case of consents, it will be the same challenge with all the actors involved in the project.

General conclusion

General conclusion

The initiative of this thesis stemmed from several personal reasons, especially the curiosity to see what characterizes the success of digital technologies outside my country, specifically in emergent countries. Then, of a scientific nature, came the research question that emerged from the observation of a problem in the field of drug allergies.

The initial objective of this thesis, which was sought for the first two years in collaboration with a company, was to explore different use cases of blockchain in healthcare. Later, these objectives were modified because the cases that had been identified could not be started. Even for the case that we considered, we could not fully evaluate the relevance of blockchain in a real situation because of several external events that slowed the project.

I then reflected on issues, such as adoption and quality of information, with the main guideline being the need to propose actionable knowledge, which is not the case in current research. This modification is also not a blockage, because we believe that the elements that have been the subject of our reflection here allow us to clarify the needs so that the integration of the blockchain is done most effectively. This corresponds to the model of “organized anarchy” (March), which stipulates that an existing technology seeks the problems that it will address (Lomi & Harrison, 2012).

The first paper on adoption allowed us to highlight the content, benefits, and drivers of DAC adoption. These elements contributed to the proposal of several research themes and allowed us to build the application by taking into account the elements that can effectively promote DAC adoption by patients and physicians. Among the adoption factors, our attention was focused on the contextual elements mentioned several times by the interviewees, and we have launched a more in-depth reflection on this subject by initiating an experimental study that is ongoing and aims to analyze the variability of benefits and privacy concerns depending on the context, as well as their impact on the intention to use.

In paper 4 we focus on the quality of information and how to prevent related problems during the design of the application. We used the affordances perspective that allowed us to define information quality as the result of interactions between users and the system or application that contains the information.

These elements of reflection are relevant to the case of drug allergy information, especially with regard to the quality of the information. The fact that we focused on a single application represents the main limitation of this work in terms of quantity of data, comparability, and more generally the fact that the objective of the thesis on blockchain has been diverted.

In terms of research perspectives, we plan to continue the initial thesis project on the exploration of blockchain use cases in health with the addition of the case of drug allergy and the case of consent traceability. We hope with this work to propose a comparative approach to the governance of a blockchain ecosystem.

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REFERENCES

Abd-Alrazaq, A. A., Bewick, B. M., Farragher, T., & Gardner, P. (2019). Factors that affect the use of electronic personal health records among patients: a systematic review. *International journal of medical informatics*, *126*, 164-175.

Abernethy, M. A., & Stoelwinder, J. U. (1990). The relationship between organisation structure and management control in hospitals: an elaboration and test of Mintzberg's professional bureaucracy model. *Accounting, Auditing & Accountability Journal*, *3*(3), 0-0.

Adler-Milstein, J., Holmgren, A. J., Kralovec, P., Worzala, C., Searcy, T., & Patel, V. (2017). Electronic health record adoption in US hospitals: the emergence of a digital "advanced use" divide. *Journal of the American Medical Informatics Association*, *24*(6), 1142-1148.

Agarwal, R., Gao, G., DesRoches, C., & Jha, A. K. (2010). Research commentary—The digital transformation of healthcare: Current status and the road ahead. *Information Systems Research*, *21*(4), 796-809.

Agbo, C. C., Mahmoud, Q. H., & Eklund, J. M. (2019). Blockchain Technology in Healthcare: A Systematic Review. *Healthcare*, *7*, 56.

Aken, J. E. v. (2004). Management research based on the paradigm of the design sciences: the quest for field-tested and grounded technological rules. *Journal of management studies*, *41*(2), 219-246.

Albert, W., & Tullis, T. (2013). *Measuring the user experience: collecting, analyzing, and presenting usability metrics* (Newnes ed.). Newnes.

AlHamad, A. Q., Al Omari, F., & AlHamad, A. Q. (2014). Recommendation for Managing Patients' Privacy in an Integrated Health Information Network. *Journal of Information Technology & Economic Development*, *5*(1).

Andrikopoulou, E., Scott, P. J., & Herrera, H. (2020). Mixed methods protocol for a realist evaluation of electronic personal health records design features and use to support medication adherence (ePHRma). *BMJ health & care informatics*, *27*(1).

Angst, C. M., & Agarwal, R. (2009a). Adoption of electronic health records in the presence of privacy concerns: The elaboration likelihood model and individual persuasion. *Mis Quarterly*, *33*(2), 339-370.

Angst, C. M., & Agarwal, R. (2009b). Adoption of electronic health records in the presence of privacy concerns: The elaboration likelihood model and individual persuasion. *MIS quarterly*, 339-370.

Apter, A. J., Kinman, J. L., Bilker, W. B., Herlim, M., Margolis, D. J., Lautenbach, E., Hennessy, S., & Strom, B. L. (2004). Represcription of penicillin after allergic-like events. *Journal of Allergy and Clinical Immunology*, *113*(4), 764-770.

References

Archer, N., & Cocosila, M. (2014). Canadian patient perceptions of electronic personal health records: an empirical investigation. *Communications of the Association for Information Systems*, *34*(1), 20.

Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K. A., & Straus, S. E. (2011). Personal health records: a scoping review. *Journal of the American Medical Informatics Association*, *18*(4), 515-522.

Archer, N., Fevrier-Thomas, U., Lokker, C., McKibbon, K. A., & Straus, S. E. (2011). Personal health records: a scoping review. *Journal of the American Medical Informatics Association*, *18*(4), 515-522.

Audet, A.-M., Doty, M. M., Peugh, J., Shamasdin, J., Zapert, K., & Schoenbaum, S. (2004). Information technologies: when will they make it into physicians' black bags? *Medscape General Medicine*, *6*(4).

Avison, D. E., Davison, R. M., & Malaurent, J. (2018). Information systems action research: Debunking myths and overcoming barriers. *Information & management*, *55*(2), 177-187.

Azarm, M., Backman, C., Kuziemsky, C., & Peyton, L. (2017). Breaking the healthcare interoperability barrier by empowering and engaging actors in the healthcare system. *Procedia computer science*, *113*, 326-333.

Bagozzi, R. P. (2007). The legacy of the technology acceptance model and a proposal for a paradigm shift. *Journal of the Association for Information Systems*, *8*(4), 3.

Baiardini, I., Braido, F., Fassio, O., Calia, R., Canonica, G. W., Romano, A., & Group, D.-Q. P. R. I. (2011). Development and validation of the drug hypersensitivity quality of life questionnaire. *Annals of Allergy, Asthma & Immunology*, *106*(4), 330-335.

Balasubramanian, S., Shukla, V., Sethi, J. S., Islam, N., & Saloum, R. (2021). A readiness assessment framework for Blockchain adoption: A healthcare case study. *Technological Forecasting and Social Change*, *165*, 120536.

Bangor, A., Kortum, P. T., & Miller, J. T. (2008). An empirical evaluation of the system usability scale. *Intl. Journal of Human–Computer Interaction*, *24*(6), 574-594.

Barton, L., Futtermenger, J., Gaddi, Y., Kang, A., Rivers, J., Spriggs, D., Jenkins, P. F., Thompson, C. H., & Thomas, J. S. (2012). Simple prescribing errors and allergy documentation in medical hospital admissions in Australia and New Zealand. *Clinical Medicine*, *12*(2), 119-123.

Baskerville, R., Baiyere, A., Gregor, S., Hevner, A., & Rossi, M. (2018). Design science research contributions: Finding a balance between artifact and theory. *Journal of the Association for Information Systems*, *19*(5), 3.

Baskerville, R. L., & Myers, M. D. (2002). Information systems as a reference discipline. *Mis Quarterly*, 1-14.

References

Baskerville, R. L., & Wood-Harper, A. T. (1996). A critical perspective on action research as a method for information systems research. *Journal of Information Technology*, *11*(3), 235-246.

Baudendistel, I., Winkler, E., Kamradt, M., Längst, G., Eckrich, F., Heinze, O., Bergh, B., Szecsenyi, J., & Ose, D. (2015). Personal electronic health records: understanding user requirements and needs in chronic cancer care. *Journal of medical Internet research*, *17*(5), e121.

Beke, F. T., Eggers, F., Verhoef, P. C., & Wieringa, J. E. (2021). Consumers' Privacy Calculus: The PRICAL Index Development and Validation. *International Journal of Research in Marketing*.

Benbasat, I., & Barki, H. (2007). Quo vadis TAM? *Journal of the Association for Information Systems*, *8*(4), 7.

Benbasat, I., & Zmud, R. W. (1999). Empirical research in information systems: The practice or relevance. *Mis Quarterly*, *23*(1), 3-16.

Blumenthal, D., & Tavenner, M. (2010). The "Meaningful Use" Regulation for Electronic Health Records. *New England Journal of Medicine*, *363*(6), 501-504.

Blut, M., Chong, A., Tsiga, Z., & Venkatesh, V. (2021). Meta-Analysis Of The Unified Theory Of Acceptance And Use Of Technology (UTAUT): Challenging Its Validity And Charting A Research Agenda In The Red Ocean. *Journal of the Association for Information Systems, Forthcoming*.

Brockow, K., Aberer, W., Atanaskovic-Markovic, M., Bavbek, S., Bircher, A., Bilo, B., Blanca, M., Bonadonna, P., Burbach, G., & Calogiuri, G. (2016). Drug allergy passport and other documentation for patients with drug hypersensitivity–An ENDA/EAACI Drug Allergy Interest Group Position Paper. *Allergy*, *71*(11), 1533-1539.

Brown, D. C., & Blessing, L. (2005). The relationship between function and affordance. International Design Engineering Technical Conferences and Computers and Information in Engineering Conference,

Buchana, Y., Garbutt, M., & Seymour, L. F. (2018). Identifying micro-level generative mechanisms of ICT-enabled performance improvement in resource-constrained healthcare organisations: A critical realist perspective. *The Electronic Journal of Information Systems in Developing Countries*, *84*(6), e12057.

Buntin, M. B., Burke, M. F., Hoaglin, M. C., & Blumenthal, D. (2011). The benefits of health information technology: a review of the recent literature shows predominantly positive results. *Health Affairs*, *30*(3), 464-471.

Burns, A. (2009). Action research. In *Qualitative research in applied linguistics* (pp. 112-134). Springer.

References

Bygstad, B., Munkvold, B. E., & Volkoff, O. (2016). Identifying generative mechanisms through affordances: a framework for critical realist data analysis. *Journal of Information Technology*, *31*(1), 83-96.

Cafazzo, J. A., Casselman, M., Hamming, N., Katzman, D. K., & Palmert, M. R. (2012). Design of an mHealth app for the self-management of adolescent type 1 diabetes: a pilot study. *Journal of medical Internet research*, *14*(3), e70.

Camponovo, G., Debetaz, S., & Pigneur, Y. (2004). A comparative analysis of published scenarios for m-business. Proceedings of the third International conference on mobile business,

Chaudhry, B., Wang, J., Wu, S., Maglione, M., Mojica, W., Roth, E., Morton, S. C., & Shekelle, P. G. (2006). Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. *Annals of internal medicine*, *144*(10), 742-752.

Chauhan, S., & Jaiswal, M. (2017). A meta-analysis of e-health applications acceptance. *Journal of Enterprise Information Management*.

Chen, Y., Huang, J., Zhang, Z., & Xie, Y. (2013). A part affordance-based approach for capturing detailed design knowledge. *Computer-Aided Design*, *45*(12), 1617-1629.

Chiriac, A. M., Banerji, A., Gruchalla, R. S., Thong, B. Y., Wickner, P., Mertes, P.-M., Terreehorst, I., & Blumenthal, K. G. (2019). Controversies in drug allergy: drug allergy pathways. *The Journal of Allergy and Clinical Immunology: In Practice*, *7*(1), 46-60. e44.

Cocosila, M., & Archer, N. (2014). Perceptions of chronically ill and healthy consumers about electronic personal health records: a comparative empirical investigation. *BMJ open*, *4*(7), e005304.

Cocosila, M., & Archer, N. (2018). Modeling consumer acceptance of electronic personal health records. *Journal of Electronic Commerce Research*, *19*(2), 119-134.

[Record #185 is using a reference type undefined in this output style.]

Corbin, J. M., & Strauss, A. (1990). Grounded theory research: Procedures, canons, and evaluative criteria. *Qualitative socioliogy*, *13*(1), 3-21.

Costa, E., Soares, A. L., & de Sousa, J. P. (2020). Industrial business associations improving the internationalisation of SMEs with digital platforms: A design science research approach. *International Journal of Information Management*, *53*, 102070.

Cruz-Correia, R., Boldt, I., Lapão, L., Santos-Pereira, C., Rodrigues, P. P., Ferreira, A. M., & Freitas, A. (2013). Analysis of the quality of hospital information systems audit trails. *BMC Medical Informatics and Decision Making*, *13*(1), 84.

Davis, F. D., Bagozzi, R. P., & Warshaw, P. R. (1989). User acceptance of computer technology: a comparison of two theoretical models. *Management science*, *35*(8), 982-1003.

References

Davison, R., Martinsons, M. G., & Kock, N. (2004). Principles of canonical action research. *Information systems journal*, *14*(1), 65-86.

De Hert, P., Papakonstantinou, V., Malgieri, G., Beslay, L., & Sanchez, I. (2018). The right to data portability in the GDPR: Towards user-centric interoperability of digital services. *Computer Law & Security Review*, *34*(2), 193-203.

Delone, W. H., & McLean, E. R. (2003). The DeLone and McLean model of information systems success: a ten-year update. *Journal of management information systems*, *19*(4), 9-30.

Delone, W. H., & Mclean, E. R. (2004). Measuring e-commerce success: Applying the DeLone & McLean information systems success model. *International Journal of electronic commerce*, *9*(1), 31-47.

Demoly, P., Adkinson, N. F., Brockow, K., Castells, M., Chiriac, A. M., Greenberger, P. A., Khan, D. A., Lang, D. M., Park, H. S., & Pichler, W. (2014). International Con sensus on drug allergy. *Allergy*, *69*(4), 420-437.

Detmer, D., Bloomrosen, M., Raymond, B., & Tang, P. (2008). Integrated personal health records: transformative tools for consumer-centric care. *BMC medical informatics and decision making*, *8*(1), 1-14.

Dick, R. S., Steen, E. B., & Detmer, D. E. (1997). *The computer-based patient record: an essential technology for health care*. National Academies Press.

Dinev, T., Xu, H., Smith, J. H., & Hart, P. (2013). Information privacy and correlates: an empirical attempt to bridge and distinguish privacy-related concepts. *European Journal of Information Systems*, *22*(3), 295-316.

Dobrow, M. J., Bytautas, J. P., Tharmalingam, S., & Hagens, S. (2019). Interoperable Electronic Health Records and Health Information Exchanges: Systematic Review. *Journal of medical Internet research*, *7*(2), e12607.

Dworzynski, K., Ardern-Jones, M., & Nasser, S. (2014). Diagnosis and management of drug allergy in adults, children and young people: summary of NICE guidance. *British medical journal*, *349*, g4852.

Featherman, M. S., Miyazaki, A. D., & Sprott, D. E. (2010). Reducing online privacy risk to facilitate e-service adoption: the influence of perceived ease of use and corporate credibility. *Journal of Services Marketing*.

Fernández-Alemán, J. L., Señor, I. C., Lozoya, P. Á. O., & Toval, A. (2013). Security and privacy in electronic health records: A systematic literature review. *Journal of Biomedical Informatics*, *46*(3), 541-562. https://doi.org/https://doi.org/10.1016/j.jbi.2012.12.003

Ferner, R., & McGettigan, P. (2020). The patient who reports a drug allergy. *British medical journal*, *368*.

References

Fettke, P., Houy, C., & Loos, P. (2010). On the relevance of design knowledge for design-oriented business and information systems engineering. *Business & Information Systems Engineering*, *2*(6), 347-358.

Fichman, R. G. (2004). Real options and IT platform adoption: Implications for theory and practice. *Information systems research*, *15*(2), 132-154.

Fischer, C., Winter, R., & Wortmann, F. (2010). Design theory. *Business & Information Systems Engineering*, *2*(6), 387-390.

Ford, E. W., Hesse, B. W., & Huerta, T. R. (2016). Personal health record use in the United States: forecasting future adoption levels. *Journal of medical Internet research*, *18*(3), e73.

Fortin-Dufour, I. (2013). Réalisme critique et désistement du crime chez les sursitaires québécois: Appréhension des facteurs structurels, institutionnels et identitaires.

Fox, G., & Connolly, R. (2018). Mobile health technology adoption across generations: Narrowing the digital divide. *Information systems journal*, *28*(6), 995-1019.

Gagnon, M.-P., Payne-Gagnon, J., Breton, E., Fortin, J.-P., Khoury, L., Dolovich, L., Price, D., Wiljer, D., Bartlett, G., & Archer, N. (2016). Adoption of electronic personal health records in Canada: perceptions of stakeholders. *International journal of health policy and management*, *5*(7), 425.

[Record #182 is using a reference type undefined in this output style.]

Gioia, D. A., Corley, K. G., & Hamilton, A. L. (2013). Seeking qualitative rigor in inductive research: Notes on the Gioia methodology. *Organizational research methods*, *16*(1), 15-31.

Gogan, J. L., Baxter, R. J., Boss, S. R., & Chircu, A. M. (2013). Handoff processes, information quality and patient safety: A trans-disciplinary literature review. *Business Process Management Journal*.

Golden, D., Moffitt, J., Nicklas, R., Freeman, T., & Graft, D. (2011). Joint Task Force on Practice Parameters, American Academy of Allergy, Asthma & Immunology (AAAAI), American College of Allergy, Asthma & Immunology (ACAAI), Joint Council of Allergy, Asthma and Immunology. Stinging insect hypersensitivity: a practice parameter update 2011. *Journal of Allergy and Clinical Immunology*, *127*(4), 852-854. e851–823.

Gomes, E., Cardoso, M., Praca, F., Gomes, L., Marino, E., & Demoly, P. (2004). Self-reported drug allergy in a general adult Portuguese population. *Clinical & Experimental Allergy*, *34*(10), 1597-1601.

Goodhue, D. L., & Thompson, R. L. (1995). Task-technology fit and individual performance. *MIS quarterly*, 213-236.

Gordon, P., Camhi, E., Hesse, R., Odlum, M., Schnall, R., Rodriguez, M., Valdez, E., & Bakken, S. (2012). Processes and outcomes of developing a continuity of care document for use as a personal health record by people living with HIV/AIDS in New York City. *International journal of medical informatics*, *81*(10), e63-e73.

References

Gorla, N., Somers, T. M., & Wong, B. (2010). Organizational impact of system quality, information quality, and service quality. *The Journal of Strategic Information Systems*, *19*(3), 207-228.

Greenhalgh, T., Hinder, S., Stramer, K., Bratan, T., & Russell, J. (2010). Adoption, non-adoption, and abandonment of a personal electronic health record: case study of HealthSpace. *BMJ*, *341*, c5814. https://doi.org/10.1136/bmj.c5814

Gregor, S. (2006). The nature of theory in information systems. *Mis Quarterly*, 611-642.

Gregor, S., & Hevner, A. R. (2013). Positioning and presenting design science research for maximum impact. *MIS quarterly*, 337-355.

Gregor, S., & Jones, D. (2007). The anatomy of a design theory. *Journal of the Association for Information Systems*, *8*(5), 312-335.

Gregor, S., Kruse, L. C., & Seidel, S. (2020). The Anatomy of a Design Principle. *Journal of the Association for Information Systems*.

Grgecic, D., Holten, R., & Rosenkranz, C. (2015). The impact of functional affordances and symbolic expressions on the formation of beliefs. *Journal of the Association for Information Systems*, *16*(7), 2.

Grisot, M., Hanseth, O., & Thorseng, A. A. (2014). Innovation of, in, on infrastructures: articulating the role of architecture in information infrastructure evolution. *Journal of the Association for Information Systems*, *15*(4), 2.

Hanseth, O., & Lyytinen, K. (2010). Design theory for dynamic complexity in information infrastructures: the case of building internet. *Journal of Information Technology*, *25*(1), 1-19.

Häyrinen, K., Saranto, K., & Nykänen, P. (2008). Definition, structure, content, use and impacts of electronic health records: a review of the research literature. *International journal of medical informatics*, *77*(5), 291-304.

Hevner, A., & Chatterjee, S. (2010). Design science research in information systems. In *Design research in information systems* (pp. 9-22). Springer.

Hevner, A. R., March, S. T., Park, J., & Ram, S. (2004). Design science in information systems research. *Mis Quarterly*, 75-105.

Hölbl, M., Kompara, M., Kamišalić, A., & Nemec Zlatolas, L. (2018). A systematic review of the use of blockchain in healthcare. *Symmetry*, *10*(10), 470.

Hsieh, H.-L., Kuo, Y.-M., Wang, S.-R., Chuang, B.-K., & Tsai, C.-H. (2017). A study of personal health record user's behavioral model based on the PMT and UTAUT integrative perspective. *International journal of environmental research and public health*, *14*(1), 8.

References

Huckvale, C., Car, J., Akiyama, M., Jaafar, S., Khoja, T., Khalid, A. B., Sheikh, A., & Majeed, A. (2010). Information technology for patient safety. *British medical journal Quality & Safety*, *19*(Suppl 2), i25-i33.

Hwang, Y. (2005). Investigating enterprise systems adoption: uncertainty avoidance, intrinsic motivation, and the technology acceptance model. *European Journal of Information Systems*, *14*(2), 150-161.

Iakovidis, I. (1998). Towards personal health record: current situation, obstacles and trends in implementation of electronic healthcare record in Europe. *International journal of medical informatics*, *52*(1-3), 105-115.

Ithnin, M., Rani, M. D. M., Latif, Z. A., Kani, P., Syaiful, A., Aripin, K. N. N., & Mohd, T. A. M. T. (2017). Mobile app design, development, and publication for adverse drug reaction assessments of causality, severity, and preventability. *JMIR mHealth and uHealth*, *5*(5), e78.

Jabagi, N., Jiang, J., MacLean, D., Chalmeau, S., & Yang, J. (2016a). Communicating to practitioners through IS research: A descriptive review.

Jabagi, N., Jiang, J., MacLean, D., Chalmeau, S., & Yang, J. (2016b). Communicating to Practitioners through IS Research: a Descriptive Review. AMCIS,

Jeng, D. J.-F., & Tzeng, G.-H. (2012). Social influence on the use of clinical decision support systems: revisiting the unified theory of acceptance and use of technology by the fuzzy DEMATEL technique. *Computers & Industrial Engineering*, *62*(3), 819-828.

Jiang, J., & Cameron, A.-F. (2020). IT-Enabled Self-Monitoring for Chronic Disease Self-Management: An Interdisciplinary Review. *MIS quarterly*, *44*(1).

Jones, T. A., & Como, J. A. (2003). Assessment of medication errors that involved drug allergies at a university hospital. *Pharmacotherapy: The Journal of Human Pharmacology and Drug Therapy*, *23*(7), 855-860.

Jozani, M., Ayaburi, E., Ko, M., & Choo, K.-K. R. (2020). Privacy concerns and benefits of engagement with social media-enabled apps: A privacy calculus perspective. *Computers in Human Behavior*, *107*, 106260.

Kahn, J. S., Aulakh, V., & Bosworth, A. (2009). What it takes: characteristics of the ideal personal health record. *Health Affairs*, *28*(2), 369-376.

Kelley, H., Chiasson, M., Downey, A., & Pacaud, D. (2011). The clinical impact of eHealth on the self-management of diabetes: a double adoption perspective. *Journal of the Association for Information Systems*, *12*(3), 4.

Ketikidis, P., Dimitrovski, T., Lazuras, L., & Bath, P. A. (2012). Acceptance of health information technology in health professionals: An application of the revised technology acceptance model. *Health Informatics Journal*, *18*(2), 124-134. https://doi.org/10.1177/1460458211435425

References

Khajouei, R., & Farahani, F. (2020). A combination of two methods for evaluating the usability of a hospital information system. *BMC Medical Informatics and Decision Making*, *20*, 1-10.

Khalil, H., Leversha, A., & Khalil, V. (2011). Drug allergy documentation-time for a change? *International journal of clinical pharmacy*, *33*(4), 610-613.

Kim, J., Jung, H., & Bates, D. W. (2011). History and Trends of. *Healthcare Informatics Research*, *17*(1), 3-17.

Kitchenham, B. A., Dyba, T., & Jorgensen, M. (2004). Evidence-based software engineering. Proceedings. 26th International Conference on Software Engineering,

Kohli, R., & Tan, S. S.-L. (2016). Electronic health records: how can IS researchers contribute to transforming healthcare? *Mis Quarterly*, *40*(3), 553-573.

Kuo, T.-T., Kim, H.-E., & Ohno-Machado, L. (2017). Blockchain distributed ledger technologies for biomedical and health care applications. *Journal of the American Medical Informatics Association*, *24*(6), 1211-1220.

Lartigau, J., Bucamp, F., & de Casaubon, D. C. (2018). PikcioChain: a new eco-system for personal data.

Laugesen, J., & Hassanein, K. (2017). Adoption of personal health records by chronic disease patients: A research model and an empirical study. *Computers in Human Behavior*, *66*, 256-272.

Laumer, S., Maier, C., & Weitzel, T. (2017). Information quality, user satisfaction, and the manifestation of workarounds: a qualitative and quantitative study of enterprise content management system users. *European Journal of Information Systems*, *26*(4), 333-360.

Lee, S. (2012). Unified Modeling Language (UML) for Database Systems and Computer Applications. *International Journal of Database Theory and Application*, *5*(1), 157-164.

Lee, Y. W., Strong, D. M., Kahn, B. K., & Wang, R. Y. (2002). AIMQ: a methodology for information quality assessment. *Information & management*, *40*(2), 133-146.

Leonardi, P. M. (2013). When does technology use enable network change in organizations? A comparative study of feature use and shared affordances. *MIS quarterly*, 749-775.

Lesar, T. S., Briceland, L., & Stein, D. S. (1997). Factors related to errors in medication prescribing. *Jama*, *277*(4), 312-317.

Lester, M., Boateng, S., Studeny, J., & Coustasse, A. (2016). Personal health records: beneficial or burdensome for patients and healthcare providers? *Perspectives in health information management*, *13*(Spring).

Li, H., Gupta, A., Zhang, J., & Sarathy, R. (2014). Examining the decision to use standalone personal health record systems as a trust-enabled fair social contract. *Decision Support Systems*, *57*, 376-386.

References

Li, H., Sarathy, R., & Xu, H. (2010). Understanding situational online information disclosure as a privacy calculus. *Journal of Computer Information Systems, 51*(1), 62-71.

Li, W., Liu, K., Yang, H., & Yu, C. (2014). Integrated clinical pathway management for medical quality improvement–based on a semiotically inspired systems architecture. *European Journal of Information Systems*, *23*(4), 400-417.

Liang, Y. (2019). Identity Verification and Management of Electronic Health Records with Blockchain Technology. 2019 IEEE International Conference on Healthcare Informatics (ICHI),

Lin, F.-R., Yang, M.-C., & Pai, Y.-H. (2002). A generic structure for business process modeling. *Business Process Management Journal*, *8*(1), 19-41.

Lindgren, R., Henfridsson, O., & Schultze, U. (2004). Design principles for competence management systems: a synthesis of an action research study. *MIS quarterly*, 435-472.

Linn, L. A., & Koo, M. B. (2016). Blockchain for health data and its potential use in health it and health care related research. ONC/NIST Use of Blockchain for Healthcare and Research Workshop. Gaithersburg, Maryland, United States: ONC/NIST,

Lomi, A., & Harrison, J. R. (2012). The garbage can model of organizational choice: Looking forward at forty. In *The Garbage Can Model of Organizational Choice: Looking Forward at Forty* (pp. 3-17). Emerald Group Publishing Limited.

Lunenburg, F. C. (2012). Organizational structure: Mintzberg's framework. *International journal of scholarly, academic, intellectual diversity*, *14*(1), 1-8.

Maier, J. R., & Fadel, G. M. (2009a). Affordance-based design methods for innovative design, redesign and reverse engineering. *Research in Engineering Design*, *20*(4), 225.

Maier, J. R., & Fadel, G. M. (2009b). Affordance based design: a relational theory for design. *Research in Engineering Design*, *20*(1), 13-27.

Majchrzak, A., & Markus, M. L. (2012). Technology affordances and constraints in management information systems (MIS). *Encyclopedia of Management Theory,(Ed: E. Kessler), Sage Publications, Forthcoming*.

Majchrzak, A., Markus, M. L., & Wareham, J. (2016). Designing for digital transformation: Lessons for information systems research from the study of ICT and societal challenges. *Mis Quarterly*, *40*(2), 267-277.

Mandviwalla, M. (2015). Generating and justifying design theory. *Journal of the Association for Information Systems*, *16*(5), 3.

Mantzana, V., Themistocleous, M., Irani, Z., & Morabito, V. (2007). Identifying healthcare actors involved in the adoption of information systems. *European Journal of Information Systems*, *16*(1), 91-102.

References

Markus, M. L., Majchrzak, A., & Gasser, L. (2002). A design theory for systems that support emergent knowledge processes. *MIS quarterly*, 179-212.

Markus, M. L., & Mentzer, K. (2014). Foresight for a responsible future with ICT. *Information Systems Frontiers*, *16*(3), 353-368.

Markus, M. L., & Silver, M. S. (2008). A foundation for the study of IT effects: A new look at DeSanctis and Poole's concepts of structural features and spirit. *Journal of the Association for Information Systems*, *9*(10), 5.

Matricardi, P. M., Dramburg, S., Alvarez-Perea, A., Antolín-Amérigo, D., Apfelbacher, C., Atanaskovic-Markovic, M., Berger, U., Blaiss, M. S., Blank, S., & Boni, E. (2019). The Role of Mobile Health Technologies in Allergy Care: an EAACI Position Paper. *Allergy*.

Mayer, R. C., Davis, J. H., & Schoorman, F. D. (1995). An integrative model of organizational trust. *Academy of management review*, *20*(3), 709-734.

Maymounkov, P., & Mazieres, D. (2002). Kademlia: A peer-to-peer information system based on the xor metric. International Workshop on Peer-to-Peer Systems,

Medvidovic, N., Rosenblum, D. S., Redmiles, D. F., & Robbins, J. E. (2002). Modeling software architectures in the unified modeling language. *ACM Transactions on Software Engineering and Methodology (TOSEM)*, *11*(1), 2-57.

Mentzer, J. T. (2008). Rigor versus relevance: why would we choose only one? *Journal of Supply Chain Management*, *44*(2), 72.

Mettler, T. (2016). Anticipating mismatches of HIT investments: Developing a viability-fit model for e-health services. *International journal of medical informatics*, *85*(1), 104-115.

Mettler, T. (2018). Contextualizing a professional social network for health care: Experiences from an action design research study. *Information systems journal*, *28*(4), 684-707.

Mintzberg, H. (1979). *The structure of organizations: A synthesis of the research*. Prentice-Hall.

Neely, M. P., & Cook, J. S. (2011). Fifteen years of data and information quality literature: Developing a research agenda for accounting. *Journal of Information Systems*, *25*(1), 79-108.

Nguewo Ngassam, R. G., Ologeanu-Taddei, R., Lartigau, J., & Bourdon, I. (2020). A Use Case of Blockchain in Healthcare: Allergy Card. In *Blockchain and Distributed Ledger Technology Use Cases* (pp. 69-94). Springer.

Noblin, A. M., Wan, T. T., & Fottler, M. (2012). The impact of health literacy on a patient's decision to adopt a personal health record. *Perspectives in Health Information Management/AHIMA, American Health Information Management Association*, *9*(Fall).

Norman, D. A. (1999). Affordance, conventions, and design. *interactions*, *6*(3), 38-43.

References

Norman, P., Boer, H., & Seydel, E. R. (2005). Protection motivation theory. *Predicting health behaviour*, *81*, 126.

Oborn, E., Barrett, M., & Davidson, E. (2011). Unity in diversity: Electronic patient record use in multidisciplinary practice. *Information systems research*, *22*(3), 547-564.

Ologeanu-Taddei, R., Wessel, L., & Bourdon, I. (2019). Persistent Paradoxes in Pluralistic Organizations: A Case Study of Continued Use of Shadow-IT in a French Hospital.

Omary, Z., Mtenzi, F., Wu, B., & O'Driscoll, C. (2011). Ubiquitous healthcare information system: Assessment of its impacts to patient's information. *International Journal for Information Security Research*, *1*(2), 71-77.

Pawankar, R., Holgate, S., Canonica, G., Lockey, R. F., & Blaiss, M. (2013). WAO white book on allergy 2013 update. *World Allergy Organization*.

Pawson, R. (2006). *Evidence-based policy: a realist perspective*. sage.

Payton, F. C., Pare, G., Le Rouge, C. M., & Reddy, M. (2011). Health care IT: Process, people, patients and interdisciplinary considerations. *Journal of the Association for Information Systems*, *12*(2), 4.

Pedersen, A. B., Risius, M., & Beck, R. (2019). A Ten-Step Decision Path to Determine When to Use Blockchain Technologies. *MIS Quarterly Executive*, *18*(2).

Peffers, K., Tuunanen, T., Rothenberger, M. A., & Chatterjee, S. (2007). A design science research methodology for information systems research. *Journal of management information systems*, *24*(3), 45-77.

Petty, G. (2009). *Evidence-based teaching*. Nelson Thornes.

Pfeffer, J., & Sutton, R. I. (2006). Evidence-based management. *Harvard business review*, *84*(1), 62.

Pozzi, G., Pigni, F., & Vitari, C. (2014a). Affordance theory in the IS discipline: A review and synthesis of the literature.

Pozzi, G., Pigni, F., & Vitari, C. (2014b). Affordance theory in the IS discipline: A review and synthesis of the literature. AMCIS 2014 Proceedings,

Qingzhong, L., Han, Y., & Zhongfan, M. (2003). A framework for comparing business process modelling languages in web services environment. *Computational and structural biotechnology journal*, *23*.

Rabah, K. (2017). Challenges & Opportunities for Blockchain Powered Healthcare Systems: A Review. *Mara Research Journal of Medicine & Health Sciences-ISSN 2523-5680*, *1*(1), 45-52.

References

Roehrs, A., Da Costa, C. A., da Rosa Righi, R., & De Oliveira, K. S. F. (2017). Personal health records: a systematic literature review. *Journal of medical Internet research*, *19*(1), e13.

Rogers, E. M., & Hunt, S. (1995). The Free Press. *New York*.

Rogers, R. W. (1975). A protection motivation theory of fear appeals and attitude change1. *The journal of psychology*, *91*(1), 93-114.

Sackett, D. L. (1997). Evidence-based medicine. Seminars in perinatology,

[Record #236 is using a reference type undefined in this output style.]

Saultz, J. W. (2003). Defining and measuring interpersonal continuity of care. *The Annals of Family Medicine*, *1*(3), 134-143.

Scapin, D. L., & Bastien, J. C. (1997). Ergonomic criteria for evaluating the ergonomic quality of interactive systems. *Behaviour & information technology*, *16*(4-5), 220-231.

Sein, M., Henfridsson, O., Purao, S., Rossi, M., & Lindgren, R. (2011). Action design research. *Mis Quarterly*, *35*(1), 37-56.

Sekimoto, M., Imanaka, Y., Kitano, N., Ishizaki, T., & Takahashi, O. (2006). Why are physicians not persuaded by scientific evidence? A grounded theory interview study. *BMC Health Services Research*, *6*(1), 92.

Shamala, P., Ahmad, R., Zolait, A., & Sedek, M. (2017). Integrating information quality dimensions into information security risk management (ISRM). *Journal of Information Security and Applications*, *36*, 1-10.

Sheng, H., Nah, F. F.-H., & Siau, K. (2008). An experimental study on ubiquitous commerce adoption: Impact of personalization and privacy concerns. *Journal of the Association for Information Systems*, *9*(6), 15.

Sherer, S. A. (2014). Advocating for action design research on IT value creation in healthcare. *Journal of the Association for Information Systems*, *15*(12), 2.

Sieverink, F., Kelders, S., Braakman-Jansen, A., & van Gemert-Pijnen, J. (2019). Evaluating the implementation of a personal health record for chronic primary and secondary care: a mixed methods approach. *BMC Medical Informatics and Decision Making*, *19*(1), 241.

Simon, H. A. (1980). Cognitive science: The newest science of the artificial. *Cognitive science*, *4*(1), 33-46.

Sligo, J., Gauld, R., Roberts, V., & Villa, L. (2017). A literature review for large-scale health information system project planning, implementation and evaluation. *International journal of medical informatics*, *97*, 86-97.

Smith, I., Hicks, C., & McGovern, T. (2020). Adapting Lean methods to facilitate stakeholder engagement and co-design in healthcare. *British medical journal*, *368*.

References

Smith, J., Bekker, H., & Cheater, F. (2011). Theoretical versus pragmatic design in qualitative research. *Nurse researcher*, *18*(2), 39-51.

Sonnenberg, C., & vom Brocke, J. (2012, 2012//). Evaluations in the Science of the Artificial – Reconsidering the Build-Evaluate Pattern in Design Science Research. Design Science Research in Information Systems. Advances in Theory and Practice, Berlin, Heidelberg.

Spagnoletti, P., Resca, A., & Lee, G. (2015). A design theory for digital platforms supporting online communities: a multiple case study. *Journal of Information Technology*, *30*(4), 364-380.

Spears, J. L., & Barki, H. (2010). User participation in information systems security risk management. *Mis Quarterly*, 503-522.

Strong, D. M., & Volkoff, O. (2010). Understanding Organization—Enterprise system fit: A path to theorizing the information technology artifact. *Mis Quarterly*, 731-756.

Strong, D. M., Volkoff, O., Johnson, S. A., Pelletier, L. R., Tulu, B., Bar-On, I., Trudel, J., & Garber, L. (2014). A theory of organization-EHR affordance actualization. *Journal of the Association for Information Systems*, *15*(2), 2.

Studeny, J., & Coustasse, A. (2014). Personal health records: is rapid adoption hindering interoperability? *Perspectives in Health Information Management*, *11*(Summer).

Sun, J., & Lu, J. (2014). An empirical study on user acceptance of healthcare website. *International Journal of Networking and Virtual Organisations 12*, *14*(1-2), 57-73.

Swartz, N. (2004). A prescription for electronic health records. *Information Management*, *38*(4), 20.

Tang, P. C., Ash, J. S., Bates, D. W., Overhage, J. M., & Sands, D. Z. (2006). Personal health records: definitions, benefits, and strategies for overcoming barriers to adoption. *Journal of the American Medical Informatics Association*, *13*(2), 121-126.

Thomas, B. H., Quirchmayr, G., & Piekarski, W. (2003). Through-walls communication for medical emergency services. *International Journal of Human-Computer Interaction*, *16*(3), 477-496.

Thompson, M., & Venters, W. (2021). Platform, or technology project? A spectrum of six strategic 'plays' from UK government IT initiatives and their implications for policy. *Government Information Quarterly*, 101628.

Tilly, R., Posegga, O., Fischbach, K., & Schoder, D. (2017). Towards a conceptualization of data and information quality in social information systems. *Business & Information Systems Engineering*, *59*(1), 3-21.

van Velsen, L., Tabak, M., & Hermens, H. (2017). Measuring patient trust in telemedicine services: Development of a survey instrument and its validation for an anticoagulation web-service. *International journal of medical informatics*, *97*, 52-58.

References

Vance, B., Tomblin, B., Studney, J., & Coustasse, A. (2015). *Benefits and barriers for adoption of personal health records* 2015 Business and Health Administration Association Annual Conference, at the 51st Annual Midwest Business; Administration Association International Conference, Chicago, IL.,

Venable, J., Pries-Heje, J., & Baskerville, R. (2016). FEDS: a framework for evaluation in design science research. *European Journal of Information Systems*, *25*(1), 77-89.

Venkatesh, V. (2000). Determinants of perceived ease of use: Integrating control, intrinsic motivation, and emotion into the technology acceptance model. *Information systems research*, *11*(4), 342-365.

Venkatesh, V., & Bala, H. (2008). Technology acceptance model 3 and a research agenda on interventions. *Decision sciences*, *39*(2), 273-315.

Vezyridis, P., & Timmons, S. (2015). On the adoption of personal health records: some problematic issues for patient empowerment. *Ethics and Information Technology*, *17*(2), 113-124.

Villamañán, E., Larrubia, Y., Ruano, M., Herrero, A., & Álvarez-Sala, R. (2011). Strategies for improving documentation and reducing medication errors related to drug allergy. *International journal of clinical pharmacy*, *33*(6), 879-880.

Virzi, R. A. (1992). Refining the test phase of usability evaluation: How many subjects is enough? *Human factors*, *34*(4), 457-468.

Volkoff, O., & Strong, D. M. (2013). Critical realism and affordances: Theorizing IT-associated organizational change processes. *Mis Quarterly*, 819-834.

Wainwright, D. W., Oates, B. J., Edwards, H. M., & Childs, S. (2018). Evidence-Based Information Systems: A New Perspective and a Road Map for Research-Informed Practice. *Journal of the Association for Information Systems*, *19*(11), 1035-1063.

Walls, J. G., Widmeyer, G. R., & El Sawy, O. A. (1992). Building an information system design theory for vigilant EIS. *Information systems research*, *3*(1), 36-59.

Walter, Z., & Lopez, M. S. (2008). Physician acceptance of information technologies: Role of perceived threat to professional autonomy. *Decision Support Systems*, *46*(1), 206-215.

Wang, R. Y., & Strong, D. M. (1996). Beyond accuracy: What data quality means to data consumers. *Journal of management information systems*, *12*(4), 5-33.

Wang, X., White, L., Chen, X., Gao, Y., Li, H., & Luo, Y. (2015). An empirical study of wearable technology acceptance in healthcare. *Industrial Management & Data Systems*.

Watbled, L., Marcilly, R., Guerlinger, S., Bastien, J.-M. C., Beuscart-Zéphir, M.-C., & Beuscart, R. (2018). Combining usability evaluations to highlight the chain that leads from usability flaws to usage problems and then negative outcomes. *Journal of biomedical informatics*, *78*, 12-23.

References

Whetstone, M., & Goldsmith, R. (2009). Factors influencing intention to use personal health records. *International Journal of Pharmaceutical and Healthcare Marketing*, *3*(1), 8-25.

Wiljer, D., Urowitz, S., Apatu, E., DeLenardo, C., Eysenbach, G., Harth, T., Pai, H., & Leonard, K. J. (2008). Patient Accessible Electronic Health Records: Exploring Recommendations for Successful Implementation Strategies [Original Paper]. *J Med Internet Res*, *10*(4), e34. https://doi.org/10.2196/jmir.1061

Witry, M. J., Doucette, W. R., Daly, J. M., Levy, B. T., & Chrischilles, E. A. (2010). Family physician perceptions of personal health records. *Perspectives in health information management/AHIMA, American Health Information Management Association*, *7*(Winter).

Wu, J. (2016). Healthcare system-use behavior: a systematic review of ITs determinants. *Journal of International Technology and Information Management*, *25*(4), 5.

Wüst, K., & Gervais, A. (2018). Do you need a Blockchain? Crypto Valley Conference on Blockchain Technology (CVCBT),

Xu, R., Frey, R. M., Fleisch, E., & Ilic, A. (2016). Understanding the impact of personality traits on mobile app adoption–Insights from a large-scale field study. *Computers in Human Behavior*, *62*, 244-256.

Zhang, X., Liu, S., Chen, X., Wang, L., Gao, B., & Zhu, Q. (2018). Health information privacy concerns, antecedents, and information disclosure intention in online health communities. *Information & management*, *55*(4), 482-493.

[Record #109 is using a reference type undefined in this output style.]

Zhu, Y., Li, Y., Wang, W., & Chen, J. (2010). What leads to post-implementation success of ERP? An empirical study of the Chinese retail industry. *International Journal of Information Management*, *30*(3), 265-276.

Zubaydi, H. D., Chong, Y.-W., Ko, K., Hanshi, S. M., & Karuppayah, S. (2019). A review on the role of blockchain technology in the healthcare domain. *Electronics*, *8*(6), 679.

Zwaanswijk, M., Verheij, R. A., Wiesman, F. J., & Friele, R. D. (2011). Benefits and problems of electronic information exchange as perceived by health care professionals: an interview study. *BioMed Central Health Services Research*, *11*(1), 256.

APPENDICES

Appendix 1

Une théorie du design pour les technologies de l'information en santé

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Résumé :

L'importance des technologies de l'information en santé a longuement été discutée dans la littérature tant sur le plan clinique que sur les plans financiers et organisationnels. Pourtant, leur adoption reste faible malgré le nombre important d'études réalisées sur les modèles d'adoption des technologies de l'information en santé. L'objectif de cet article est de combiner les modèles d'acceptabilité à la théorie du design pour élaborer des principes et des règles de design actionnables dans des projets de développement des technologies de l'information en santé. Cet article formule et synthétise plusieurs éléments de la littérature sur l'acceptabilité des technologies de l'information en santé en transformant les déterminants d'acceptabilité en principes du design et ces derniers en règles du design pour les rendre applicables et ajustables. Les prochaines études pourraient dès lors permettre la validation et l'évaluation de cette théorie du design par l'analyse de l'impact de l'application de ces principes.

Mots clés :

Technologie de l'information en santé, théorie du design, acceptabilité, principes de conception règles de conception

1. Introduction

Les technologies de l'information en santé sont devenues incontournables dans le parcours de soin des individus car elles permettent la facilité d'accès aux informations ainsi que la réduction des coûts et des erreurs médicales (Buntin et al., 2011; Swartz, 2004). Ces technologies permettent l'enregistrement, le traitement, le partage, la validation et la sécurisation des informations qui touchent à la santé des individus. Elles sont de plusieurs ordres parmi lesquels les objets connectés (Wang et al., 2015), les applications pour la gestion administrative des patients (admission, facturation, etc.)(Audet et al., 2004), les dossiers électroniques de santé qui sont tenus par les établissements de santé ou qui constituent le carnet de santé du patient, les dossiers personnels de santé qui sont soient des applications d'usage courant utilisées par les individus pour veiller sur leurs constantes de base (poids, groupe sanguin, cycle menstruel, gestion grossesse, tension, calories, glycémie, etc.) soient des dossiers de santé ouverts aux patients via des portails patients (Kelley et al., 2011; Sieverink et al., 2019; Tang et al., 2006). Les études en informatique médicale et en système d'information ont généralement présentés les impacts positifs de ces applications sur le plan clinique, financier et organisationnel, mais malgré l'importance de ces technologies, leur adoption reste faible surtout en ce qui concerne les dossiers personnel de santé qui impliquent les individus (Buntin et al., 2011). Cette faible adoption a été attribuée à plusieurs facteurs présentés dans la littérature sur l'acceptabilité des applications en santé tels que l'utilité perçue, l'interopérabilité, la confidentialité des données ou la menace perçue par les médecins qui pensent que la technologie peut leur enlever le contrôle sur leur travail (Kahn et al., 2009).

Par ailleurs, en système d'information, il y'a d'une part les théories comportementales (théories prédictives, interprétatives, explicatives et d'analyse) et d'autre part les théories de la conception. Cependant, ces deux tendances revêtent un caractère complémentaire car chacune devrait informer l'autre (Hevner et al., 2004). La littérature sur les déterminants de l'acceptabilité des applications de santé serait un intrant capital dans le développement des théories de la conception d'après Hevner et Al (2010) lorsqu'ils évoquent le fait que les théories telles que TAM pourraient informer les chercheurs en sciences du design à créer des

artefacts qui permettent aux organisations de surmonter les problèmes d'acceptabilité prédits à travers les modèles construits (Gregor & Hevner, 2013; Hevner & Chatterjee, 2010). Pourtant, tandis que la littérature sur l'acceptabilité des technologies de l'information en santé est riche (Wu, 2016), il n'existe pas encore un ensemble de principes pour la conception des applications de santé basé sur les modèles d'adoption alors que l'approche de la théorie du design a démontré son succès en ce qui concerne les prescriptions de principes de conception pour les systèmes émergents (Hevner & Chatterjee, 2010). Par ailleurs, les travaux sur le design, l'implémentation et l'usage des technologies de l'information en santé ont été compté par Agarwal et al., (2010) parmi les trois domaines majeurs qui méritent de faire l'objet des futures recherches en santé et l'utilisation des théories de design permettraient de réduire les risques d'échecs des projets de conception et d'implémentation des technologies de l'information en santé (Sherer, 2014).

La présente étude a pour objectif de formaliser des règles du design pour les technologies de l'information en santé qui adressent le problème d'acceptabilité prédits dans la littérature. Ainsi, elle propose des principes de conception pour les applications de santé en se basant sur les modèles de l'adoption des technologies de l'information en santé. Les principes qui en ressortent sont transformés en règles de design, en suivant le modèle utilisé par Hanseth et Lyytinen (2010) pouvant être utilisés dans les projets de conception des applications de santé et ajustés en fonction des résultats obtenus après application dans des projets.

Les prochaines parties présenteront successivement les technologies de l'information en santé, le cadre de sciences de design utilisé, les principes et les règles de design ainsi que les perspectives de recherche rattachées à ce travail.

2. Les technologies de l'information en santé

Les technologies de l'information en santé ont pour but la collecte, le traitement, la sauvegarde, le partage et l'utilisation des informations dans un environnement de santé (Chauhan & Jaiswal, 2017). Comme exemple de technologies de l'information, Ketikidis et al.(2012) parlent des dossiers numériques de santé, qui sont par ailleurs inclus par d'autres auteurs dans la catégorie des applications en santé au même titre que les applications d'aide à la décision clinique, les dossiers personnels de santé, les applications de télémédecine ou les

applications de gestion administrative des patients (Buntin et al., 2011; Chaudhry et al., 2006).

Dans cette section, nous allons premièrement présenté l'importance des technologies de l'information en santé ensuite nous allons présenter les problèmes actuels liés à ces technologies.

2.1Importance des technologies de l'information en santé

A cause du caractère fragmenté des soins, les technologies de l'information apparaissent comme une véritable opportunité pour le domaine de la santé car elles permettent de réduire les coûts, d'augmenter la performance clinique des médecins ainsi que la sécurité des patients (Buntin et al., 2011).

Au centre de la définition des technologies de l'information en santé, l'accent est mis sur l'information de santé avec pour finalité la disponibilité et la sécurité de cette information pour tous les usages qui en sont fait. A côté de la question de disponibilité de l'information de santé, la problématique d'accessibilité a été longuement discutée dans la littérature parce que l'accès à l'information médicale des patients est un gage de qualité des soins (Swartz, 2004). En effet, le partage des informations de santé entre différents professionnels permettrait de réduire le risque d'erreur médicale lié à la problématique d'accès de ces informations (Swartz, 2004). Une grande partie des erreurs médicales serait liée au fait que le médecin prenant en charge le patient à un moment donné ne dispose pas forcément de toutes les informations de l'historique médical généré par les précédentes prises en charge de ce patient (Sherer, 2014; Swartz, 2004).

L'importance des questions liées à l'information de santé se manifeste par de nombreuses études y relatives concernant les sujets tels que *(Chauhan & Jaiswal, 2017; Iakovidis, 1998)* :

- *Accessibilité et disponibilité de l'information,*
- *Fiabilité de l'information,*
- *Confidentialité et traçabilité.*

Ces différents sujets ont été combinés pour former avec d'autres éléments les caractéristiques idéales des applications en santé comme les dossiers personnels de santé (Iakovidis, 1998).

- *Performance de l'application*
- *Habilitation ou autonomisation du patient*
- *Implication des professionnels de santé*
- *Utilisabilité et flexibilité de l'outil*
- *Intégration à d'autres systèmes*

Bien que connues, ces caractéristiques font encore défaut dans les applications actuelles.

2.2 **L'acceptabilité des technologies de l'information en santé**

Plusieurs problèmes liés aux technologies de l'information en santé sont cités par de nombreux auteurs et praticiens du domaines de l'informatique médicale ou des systèmes d'information de santé notamment l'usabilité, l'interopérabilité (Kohli & Tan, 2016) et de traçabilité des informations (Cruz-Correia et al., 2013). Pourtant, ces différents éléments semblent être déterminant pour l'utilisation des applications par les patients, les professionnels de santé et toutes les autres parties prenantes du secteur de la santé. En conséquence, les besoins des différents utilisateurs ne sont pas comblés et il en résulte l'échec des projets de conception et d'implémentation des applications manifestés par la faible adoption ou la résistance à l'utilisation dans les milieux hospitaliers ou dans les contextes d'utilisation des applications.

Plusieurs études ont été menées pour construire et valider les modèles d'adoption des technologies de l'information en santé et de nombreux déterminants ont été identifiés (Wu, 2016). Pourtant aucun changement majeur n'a été remarqué dans le sens que le constat reste toujours le même sur le fait du faible taux d'adoption des applications de santé, et des technologies de l'information de santé en général (Buntin et al., 2011).

Dans les implications pratiques présentées par les études sur les déterminants d'adoption des technologies de l'information en santé, les auteurs parlent de l'applicabilité à la pratique pour

prévenir la faible adoption, une assertion similaire est retrouvée dans le travail de Hevner et Al. (Baskerville et al., 2018; Hevner et al., 2004) lorsqu'ils proposent l'approche du design science comme complémentaire aux théories comme celles sur l'acceptabilité pour développer des artefacts qui résolvent les questions d'acceptabilité.

3. Une théorie du design pour les technologies de l'information en santé

Le courant des théories de design permet de résoudre des problèmes pratiques en se basant sur la littérature selon la méthodologie proposée par (Gregor & Jones, 2007) et utiliser par (Hanseth & Lyytinen, 2010)

Dans cette section, nous présentons premièrement le cadre général de la théorie du design, la méthodologie de l'étude et ensuite nous présentons la théorie du design des technologies de l'information en santé.

3.1 **Cadre général de la théorie du design**

Les recherches en sciences du design tirent leurs origines des sciences de l'artificiel (Simon, 1980). Plusieurs auteurs travaillant sur ce sujet soutiennent que l'intérêt des recherches en système d'information c'est leur applicabilité à la conception (Benbasat & Zmud, 1999).

En effet, en dehors des théories explicatives, d'analyses et prédictives, les chercheurs en systèmes d'information se sont depuis plusieurs années intéressés à la théorie de la conception et de l'action pour définir une méthode scientifique claire de création de la connaissance par la conception et l'évaluation des artefacts (Spagnoletti et al., 2015) qui permettrait de répondre aux problèmes concrets des organisations ou des professionnels.

L'artefact qui peut désigner aussi bien un objet (instance d'un modèle), une méthode, un logiciel ou une application a été longtemps considéré comme le focus principal d'une théorie de la conception (Mandviwalla, 2015). D'autres auteurs envisagent cependant la théorie de la conception autrement que par la description de l'artefact car, il est souvent plus facile de valoriser sur le plan scientifique des propositions testables et falsifiables (Fischer et al., 2010; Mandviwalla, 2015) qui sont en réalité des principes qui ont permis ou qui peuvent permettre la réalisation de l'artefact. Toutefois, la description d'un artefact en lui-même reste une contribution valable lorsque l'apport unique est bien défini. En effet, la description d'un

artefact peut renseigner sur les principes qui ont été mis en œuvre pour sa conception (Sonnenberg & vom Brocke, 2012).

Depuis la publication de l'article de Wall et Al, le mot de théorie du design a été souvent employé pour désigner un ensemble de concepts (1992), de croyances ou de lois permettant aux concepteurs de faire correspondre les problèmes de conception aux solutions pour atteindre des objectifs de conception bien précis (Hanseth & Lyytinen, 2010). Plus tard, d'autres auteurs ont travaillé sur les composantes d'une théorie du design parmi lesquelles on retrouve : le problème et les connaissances justificatives du problème ou théorie du noyau, le but et la portée ainsi que les principes de formes et de fonction (Gregor & Jones, 2007).

La théorie du noyau est le cœur d'une théorie de la conception qui permet d'émettre des postulats falsifiables pour le processus de conception ou l'artefact qui en ressort (Gregor, 2006). Elle permet d'informer le problème de design, non seulement en le justifiant, mais aussi en y apportant des éléments de solution (Hanseth & Lyytinen, 2010; Spagnoletti et al., 2015).

Notre objectif de design étant de développer des principes de conception qui permettent d'adresser l'acceptabilité des applications de santé, nous nous intéressons ci-dessous à la littérature sur l'acceptabilité des applications de santé.

3.2 **Méthodologie**

La présente étude utilise le cadre de design science présenté ci-dessus pour lire et interpréter les résultats des études relatives à l'adoption des technologies de l'information en santé.

Nous nous basons principalement sur la littérature existante relatives aux déterminants d'adoption. Nous avons fait les recherches premièrement sur Google Scholar ensuite nous avons affiné en allant dans la base de données ABI Inform. La formule utilisée est la suivante:

(« healthcare information technology » AND (Adoption OR Acceptance))

Pour les études avant 2016 nous utilisé la revue de littérature de Wu (2016) et pour les années au-delà de 2016, nous avons effectué ensuite filtré la date pour récupérer les articles publiés au-delà de 2016 revu par les pairs, qui traitent des déterminants d'adoption des technologies de l'information en santé. Nous n'avons obtenu aucun résultat pour les critères de recherche

proposé car les études trouvées ne traitaient pas du principal focus sur les déterminants d'adoption. Nous avons donc principalement utiliser la revue de littérature de Wu cité ci-dessus.

Ensuite nous déduisons les principes et les règles de design selon le modèle proposé par Aken et Al. (2004) partant des différentes relations démontrées entre les déterminants d'adoption identifiés et l'adoption des technologies. La formulation des principes de design suivent la formulation : « Pour atteindre B, il faut prendre en compte A, C, etc durant le processus de conception »

Tandis que les principes de design répondent à la question « quoi ? », les règles de design fournissent les connaissances justificatives (Hanseth & Lyytinen, 2010). Le processus d'obtention de ces connaissances (principes et règles de design) peuvent résulter d'étude de cas, d'actions sur le terrain ou de la littérature. Dans le dernier cas il s'agit de l'extraction de règles (Aken, 2004).

4. L'acceptabilité des technologies de l'information en santé comme théorie du noyau

Les chercheurs ont largement étudiés ces dernières années les déterminants de l'acceptabilité des applications de santé au travers des modèles théoriques tels que TAM (Technology Acceptance Model), TRA (Theory of Reasoned Action), UTAUT (Unified Theory of Acceptance and use of Technology), TTF (Task and Technology Fit) (Wu, 2016).

En suivant les recommandations de Hevner et Al. (2004), nous choisissons les différents modèles d'adoption des technologies de l'information en santé comme théorie du noyau parce qu'ils informent largement la question de l'acceptabilité des applications de santé à travers de nombreuses études réalisées pour développer des modèles permettant d'identifier les facteurs déterminant l'acceptabilité de diverses technologies de l'information en santé. Au regard de la littérature, les études ont porté sur divers types de technologies mais une méta analyse réalisée par Chauhan and Jaiswal (2017) démontrent que la validité des modèles identifiés ne dépend pas de la nature des applications considérées durant l'étude ; c'est la raison pour laquelle nous considérons les déterminants répertoriés ci-dessous comme étant valides pour quel que soit le type d'application en santé.

En effet, nous pouvons définir l'acceptabilité au regard des nombreux modèles relatifs par deux principaux facteurs : l'intention d'utiliser la technologie et l'utilisation effective de cette technologie (Davis et al., 1989). Ces deux facteurs sont influencés par de nombreux facteurs liés à la technologie, la motivation, l'engagement (Venkatesh, 2000; Venkatesh & Bala, 2008), ainsi que les variables modératrices liées aux caractéristiques personnelles et environnementales du sujet étudié telles que les normes subjectives, l'âge, le sexe, le poste, etc. (Venkatesh, 2000).

Suivant la logique des études sur les théories d'acceptabilité, plusieurs travaux ont identifié des déterminants d'acceptabilité des technologies de l'information en santé. En effet, d'après les modèles classiques en système d'information, la perception de l'utilité et la perception de la facilité d'utilisation ont souvent été citées comme les principaux déterminants de l'adoption des technologies. En santé, s'il est vrai que ces déterminants restent valables, les études antérieures ont mis l'accent sur la compatibilité, la performance attendue, le risque perçu, la confiance, la crédibilité, la menace perçue qui influencent soit positivement, soit négativement les deux premiers construits précédemment cités avec des effets modérateurs liés aux caractéristiques démographiques (Wu, 2016).

La compatibilité représente le degré de correspondance du nouveau système avec les valeurs, les expériences passées ainsi que les besoins des potentiels utilisateurs (Rogers & Hunt, 1995). Plusieurs études ont démontré l'influence de ce construit sur l'attitude d'utilisation de la technologie. En effet, il faudrait qu'une technologie en santé puisse correspondre avec les processus et les outils existants. La question de la compatibilité fait donc référence à l'interopérabilité (Kohli & Tan, 2016) ou à la correspondance entre la technologie et les tâches (Goodhue & Thompson, 1995). C'est un élément important en santé pour la continuité et l'optimisation du parcours de soin des patients.

Le deuxième déterminant important est la confiance qui peut se définir comme la volonté d'une partie d'être vulnérable aux actions d'une autre partie sur la base de l'attente que l'autre accomplira une action particulière importante pour le débiteur, quelle que soit la capacité de surveiller ou de contrôler cette autre partie (Mayer et al., 1995). Les questions de confiance en ce qui concerne les technologies de l'information en santé sont très importantes et font référence à la protection des données personnelles des patients, ou tout simplement à la confiance qu'aurait l'utilisateur vis-à-vis du au système ou de son éditeur. Une technologie à

laquelle les patients et professionnels font confiance est donc plus à même d'être adoptée (AlHamad et al., 2014).

La performance attendue peut se définir comme le degré avec lequel les utilisateurs pensent qu'une technologie peut augmenter leur performance au travail. En santé, cela est particulièrement important pour les médecins qui espèrent améliorer leur travail grâce aux technologies de l'information (Jeng & Tzeng, 2012).

Le risque perçu définit la probabilité d'une conséquence négative suite à l'utilisation d'une technologie. Il est généralement comparé au bénéfice perçu préalablement à l'adoption d'une technologie. En santé, les bénéfices d'une technologie doivent être au-delà de la probabilité de défaillance du système ainsi que la sécurité des informations (Wang et al., 2015).

La menace perçue se définit comme le degré avec lequel une personne croit que l'utilisation d'un système particulier diminuerait son contrôle sur les conditions, les processus, les procédures ou le contenu de son travail. L'autonomie des professionnels de santé dans leur travail implique donc la nécessité pour une technologie de ne pas lui enlever le contrôle dans son travail (Walter & Lopez, 2008).

Pour finir avec les déterminants identifiés dans la littérature ces dernières années, la crédibilité est un élément très important dans le domaine de la santé surtout pour ce qui concerne la fiabilité des informations de patients. Ce construit influence l'adoption et l'utilisation de la technologie par les médecins qui ont besoin des informations fiables dans le processus de prise en charge des patients (Sun & Lu, 2014).

Partant des déterminants de l'acceptabilité cité plus haut, l'on peut ressortir plusieurs points importants que nous avons présenté dans le *Tableau 1* below sous formes de principes de conception.

Tableau 1. Théorie de design pour adresser l'acceptabilité des applications de santé

Objectifs de design	Créer des applications de santé qui adressent les problèmes d'acceptabilité
Fonctions du système	Les technologies de l'information en santé permettent la

	collecte, le stockage, le traitement, le partage et la sécurisation des données de santé
Théorie du noyau	L'acceptabilité des applications de santé est principalement étudié sous l'angle du modèle Theory of Acceptance Model (TAM) - La facilité d'utilisation, - La compatibilité, - La confiance, - La performance attendue, - Le risque perçu, - La menace perçue - La crédibilité.
Principes de design (PD)	Pour adresser le problème d'acceptabilité les TI en santé doivent : **PD1 :** intégrer les utilisateurs finaux dans l'identification des besoins **PD2 :** être interopérables avec les technologies existantes **PD3 :** intégrer les utilisateurs finaux dans les tests fonctionnels **PD4 :** intégrer les dispositifs d'identification et d'authentification forts **PD5:** intégrer les dispositifs pour suivre les activités dans le système

	PD6 : permettre que les utilisateurs contrôlent l'accès à leur données

4.1 **Règles de design (RD) des technologies de l'information en santé**

Les principes de design énumérés dans le *Tableau 1* guident les concepteurs à construire des applications qui prennent en compte les déterminants de l'acceptabilité. Nous discutons par la suite comment les dix (10) règles de design présentées plus bas ont été déduites pour justifier les principes de design et permettre leur ajustement et leur validation. En effet, chaque règle de design constitue une déclaration falsifiable qui pourra permettre d'ajuster les principes de design si, après application, le problème de design de départ n'est pas résolu (Hanseth & Lyytinen, 2010).

Le premier principe concernant la nécessité d'intégrer les utilisateurs finaux dans le processus d'identification des besoins correspond au déterminant d'acceptabilité relatif à la comptabilité qui intègre la compatibilité avec les besoins des utilisateurs finaux. En effet, le domaine de la santé est constitué de plusieurs parties prenantes qu'il faut prendre en compte en fonction de la cible de l'application **(RD1)** (Azarm et al., 2017; Grisot et al., 2014). Parmi eux, nous avons les professionnels de santé qui sont très spécialisés et dont les activités sont très diversifiées ce qui rend les besoins peu claires au début des projets (Kohli & Tan, 2016). Les patients quant à eux ont des situations et des parcours de santé, ainsi que des perception différentes des technologies de l'information. Le besoin identifié doit pouvoir être validé auprès d'un groupe d'utilisateurs cibles pour s'assurer qu'il est vraiment pertinent dans leur quotidien **(RD2)**.

La fragmentation du domaine de la santé se manifeste par le fait qu'il existe de nombreux logiciels et applications qui se complètent en termes d'objectifs et d'informations, il est donc important pour la continuité de soin des patients que les différents systèmes puissent être interopérables (Azarm et al., 2017). Pour cela, le deuxième principe relatif à l'interopérabilité avec les autres systèmes correspond à la nécessité pour une technologie d'être compatible avec l'existant. Dans ce cadre, des standards d'interopérabilité existent, ainsi que des solutions pour faciliter l'interfaçage des applications **(RD3)**. Pour une meilleure efficacité des standards, leur adoption doit être rendue obligatoire et prise en compte dans l'admission d'une

nouvelle technologie de l'information sur le marché **(RD4)**. De même, pour éviter une connexion application par application, un registre généralisé sur lequel toutes les applications pourront se connecter **(RD5)**.

Au même titre que l'interopérabilité, la facilité d'utilisation de l'application doit être prise en compte pendant la construction de l'application. Le troisième principe concerne l'implication des utilisateurs comme testeurs fonctionnels de l'application. Il existe des normes d'usabilité et une méthodologie impliquant les évaluations continues avec les experts et les utilisateurs pour résoudre les problèmes d'usabilité au fur et à mesure du développement **(RD6)** (Watbled et al., 2018). Par ailleurs, les tests fonctionnels, surtout lorsqu'ils sont fait en contexte d'usage permettent aussi de s'assurer de la compatibilité de la technologie avec les pratiques et les processus existants (Ologeanu-Taddei et al., 2019) afin d'éviter le contournement du système d'information par les utilisateurs **(RD7).** Une autre solution en post-implémentation pourrait permettre d'ajuster l'application à l'évolution des pratiques **(RD8)** (Zhu et al., 2010)

Le principal facteur pouvant garantir la confiance des utilisateurs en une application est très souvent basée sur l'assurance de la fiabilité et la sécurité des informations (Wu, 2016). Du point de vue du médecin, il s'agit de s'assurer qu'une information est bien fiable pour être intégrée dans sa stratégie de prise en charge du patient. Et du point de vue du patient, il est question de s'assurer que les informations ne seront effectivement accessibles que par les personnes autorisées**.** Pour y parvenir, une première étape est de contrôler l'accès à l'application via un processus d'identification approprié (Liang, 2019)**(RD9)**. Ensuite, prendre en compte les dispositions légales en lien avec les personnes autorisées à accéder aux données d'un patient **(RD10)**. La fiabilité de l'information est par ailleurs assurée par la traçabilité de chaque information entrée dans l'application (Cruz-Correia et al., 2013), en ce qui concerne notamment l'auteur de l'information **(RD11)**.

Nous résumons la correspondance des principes aux règles de design dans le **Tableau 2** ci-dessous :

Tableau 2. Correspondance entre principes et règles de design pour les technologies de l'information en santé

Principes de design (PD)	**Règles de design (RD)**	**Déterminants d'adoption adressé**

PD1 : intégrer les utilisateurs finaux dans l'identification des besoins	**RD1** : Identifier la cible d'utilisateurs de la technologie **RD2 :** Faire valider le besoin identifié par un groupe d'utilisateurs cibles	Compatibilité aux besoins, performance attendue
PD2 : être interopérables avec les technologies existantes	**RD3 :** Appliquer les standards d'interopérabilité **RD4 :** Veiller à la conformité aux standards avant la mise sur le marché **RD5 :** Assurer l'interfaçage avec une application nationale centralisée	Compatibilité avec les applications existantes, performance attendue
PD3 : intégrer les utilisateurs finaux dans les tests fonctionnels	**RD6 :** Appliquer les standards d'usabilité et effectuer les tests utilisateurs et avec les experts **RD7 :** tester en contexte d'usage **RD8 :** effectuer des ajustements en post-implémentation	Facilité d'utilisation, compatibilité aux processus et pratiques de travail existants, performance attendue
PD4 : intégrer les dispositifs d'identification et d'authentification forts	**RD9 :** Contrôler les accès à l'application par le processus d'identification	Confiance, crédibilité
PD5: intégrer les dispositifs pour suivre les activités dans le système	**RD8 :** assurer la traçabilité des informations	Confiance, crédibilité

PD6 : permettre que les utilisateurs contrôlent l'accès à leur données	**RD10 :** prendre en compte les considérations légales relatives à la confidentialité des données de santé	Confiance, crédibilité

5. **Implications, limites, perspectives et conclusion**

Partant de la remarque que l'adoption reste faible malgré les nombreuses études sur l'acceptabilité des technologies de l'information en santé, il semble premièrement nécessaire d'appliquer les différents modèles dans la pratique en les rendant actionnables par la conversion en principes de design. Ensuite il faut ces principes valider en les appliquant aux projets et en évaluant le niveau d'acceptabilité des applications qui en ressortent de ces projets. Dans ce cadre, cette étude propose l'extraction quelques principes de conception pour les technologies de l'information en santé permettant d'adresser les problèmes d'acceptabilité prévus dans la littérature. L'originalité de ce travail porte sur la formulation des principes et des règles de conception des applications en santé de sorte à les rendre opérationnels en combinant les modèles d'acceptabilité et la théorie de design.

Sur un plan théorique, ce papier complète la littérature sur les théories du design associées aux théories sur l'acceptabilité, plus particulièrement dans la littérature en santé. Partant des nombreuses études réalisées sur les déterminants de l'adoption des technologies de l'information en santé, nous avons extraits des règles de design rendant plus concret la façon de mettre en œuvre des technologies qui adressent les problèmes d'acceptabilité prédit. Sur un plan pratique, il s'agit d'un intrant important dans les projets de développement d'applications de santé.

Une limite de cette étude est que les principes n'ont pas été validés et évalués à travers des cas réels. Il s'agit toutefois d'une première étape dans un travail de recherche qui pourra se poursuivre dans les prochaines études par l'application des principes en recherche action ou par la validation des principes sur des cas déjà existants à travers des études de cas. De cette façon, il serait possible d'évaluer non seulement la théorie du design mise en œuvre mais aussi la validité des déterminants d'acceptabilité d'un point de vue purement pratique contrairement aux approches quantitatives et qualitatives qui ont souvent été utilisées.

Appendix 2

1. Context

What do you know about allergy card?

What do know about applications in healthcare? Have you ever used them? What did you think?

What do you think of the principle and the usefulness of Digital allergy documentation?

2. Ergonomics:

What do you think about the interfaces of the application?

Is it simple or are there any difficulties in use? (intuitive use?)

3. Content:

Are the fields to be filled understandable?

Are the different textual contents understandable

Would you like to add or remove any information?

4. Usage:

Would you like to use it? Why ? How ?

Do you have anything to add ?

Appendix 3 : Scenarios and Questionnaire in french (version actuelle)

Bonjour,

Cette étude est menée dans le cadre d'une recherche universitaire. Nous vous remercions d'avoir accepté de répondre aux questions.

Vos réponses resteront **strictement anonymes** et **confidentielles** et ne seront utilisées qu'à des fins académiques. Il n'y a pas de bonnes ou de mauvaises réponses. Veuillez répondre aux questions de la manière la plus **sincère et spontanée** possible, même si certaines questions peuvent sembler étranges ou répétitives. Il faudra environ 10 minutes pour remplir ce questionnaire.

Vous êtes entièrement libre de participer à cette enquête. Vous avez le droit de refuser de participer à cette enquête. Si vous décidez de participer, vous pouvez choisir de vous retirer de l'enquête à tout moment sans donner de raison.

En cliquant sur le bouton ci-dessous, vous acceptez de participer à ette enquête.

Comment procéder ?

Tout d'abord, nous vous invitons à lire l'histoire de Daniel qui a vécu une allergie en 2018. Ensuite, merci de répondre aux questions en vous mettant à la place de Daniel. Il n'y a pas de bonne ou de mauvaise réponse, seule votre avis compte. Pour certaines questions, merci d'indiquer votre degré d'accord sur une échelle de 1 à 5 (1 : fortement en désaccord, 2 : en désaccord, 3 : neutre, 4 : d'accord, 5 : tout à fait d'accord).

Merci de votre participation!

Scénario 1

Daniel a vécu un incident en 2018 qui l'a amené aux services des urgences, inconscient. Après l'administration de la pénicilline Daniel a eu une réaction allergique qui lui a provoqué

une difficulté à respirer. Peu de temps après, il a fait une crise d'urticaire et sa peau est devenue bleue. Pour traiter cette urticaire, les médecins des Urgences ont trouvé une solution rapide pour la calmer. Plus tard, Daniel a réalisé un test d'allergie qui a confirmé qu'il était allergique à la pénicilline. D'après son médecin, s'il utilise la pénicilline une nouvelle fois, il pourrait avoir les mêmes réactions que celles de la première fois, voire plus graves. Par conséquent, son médecin lui a recommandé d'éviter l'utilisation de la pénicilline dans ses traitements médicaux ultérieurs.

Daniel se rend souvent à d'autres endroits pour des vacances ou pour le travail. **Il a alors l'habitude de consulter différents médecins. À chaque visite chez ces différents médecins, on lui pose des questions sur ses antécédents médicaux dont les allergies aux médicaments.**

Récemment, un ami de Daniel lui a parlé d'une carte d'allergie numérique, qui est une application mobile permettant de tracer les informations sur les allergies aux médicaments. Cette application mobile rend l'information disponible et accessible n'importe où et n'importe quand.

L'utilisation de cette application nécessite l'enregistrement les informations d'identité du patient ainsi que les détails sur les antécédents allergiques (réactions, médicaments à risque et circonstances entourant la réaction).

Cette application fournit également des conseils aux utilisateurs pour les aider à comprendre les gérer efficacement si elles se reproduisent.

Scénario 2

Daniel a vécu un incident en 2018 qui l'a amené aux services des urgences, inconscient. Après l'administration de la pénicilline Daniel a eu une réaction allergique qui lui a provoqué une difficulté à respirer. Peu de temps après, il a fait une crise d'urticaire et sa peau est devenue bleue. Pour traiter cette urticaire, les médecins des Urgences ont trouvé une solution rapide pour la calmer. Plus tard, Daniel a réalisé un test d'allergie qui a confirmé qu'il était allergique à la pénicilline. D'après son médecin, s'il utilise la pénicilline une nouvelle fois, il pourrait avoir les mêmes réactions que celles de la première fois, voire plus graves. Par conséquent, son médecin lui a recommandé d'éviter l'utilisation de la pénicilline dans ses traitements médicaux ultérieurs.

Daniel voyage rarement, c’est plutôt une personne sédentaire. **Il a ses propres médecins qu’il consulte très souvent quand il en a besoin, car chacun de ces médecins connaît son dossier, ses antécédents médicaux dans de nombreux aspects comme les allergies médicamenteuses.**

Récemment, un ami de Daniel lui a parlé d’une carte d’allergie numérique, qui est une application mobile permettant de tracer les informations sur les allergies aux médicaments. Cette application mobile rend l’information disponible et accessible n’importe où et n’importe quand.

L'utilisation de cette application nécessite l'enregistrement les informations d'identité du patient ainsi que les détails sur les antécédents allergiques (réactions, médicaments à risque et circonstances entourant la réaction).

Cette application fournit également des conseils aux utilisateurs pour les aider à éviter les réactions allergiques et à les gérer efficacement si elles se reproduisent.

Scénario 3

Daniel a vécu un incident en 2018 qui l’a amené aux urgences, inconscient. Après l’administration de la pénicilline, Daniel a eu une réaction allergique qui lui a provoqué une crise d’urticaire. Pour traiter cette réaction, les médecins aux urgences ont trouvé une solution rapide pour calmer cette crise. Plus tard, Daniel a réalisé un test d’allergie qui a confirmé qu’il était allergique à la pénicilline. Cependant, selon son médecin, la pénicilline peut lui être prescrite prudemment.

Daniel se rend souvent à d’autres endroits pour des vacances et pour le travail. **Il a alors l’habitude de consulter différents médecins. À chaque visite chez ces différents médecins, on lui a posé des questions sur ses antécédents médicaux sur plusieurs aspects tels que les allergies aux médicaments.**

Récemment, un ami de Daniel lui a parlé d’une carte d’allergie numérique, qui est une application mobile pour suivre les informations sur les allergies aux médicaments. Cette application mobile rend l’information disponible et accessible n’importe où, n’importe quand.

L'utilisation de cette application nécessite l'enregistrement les informations d'identité du patient ainsi que les détails sur les antécédents allergiques (réactions, médicaments à risque et circonstances entourant la réaction).

Cette application fournit également des conseils aux utilisateurs pour les aider à éviter les réactions allergiques et à les gérer efficacement si elles se reproduisent.

Scénario 4

Daniel a vécu un incident en 2018 qui l'a amené aux urgences, inconscient. Après l'administration de pénicilline, Daniel a eu une réaction allergique qui lui a provoqué une crise d'urticaire. Pour traiter cette réaction, les médecins aux urgences ont trouvé une solution rapide pour calmer cette crise. Plus tard, Daniel a réalisé un test d'allergie qui a confirmé qu'il était allergique à la pénicilline. Cependant, selon son médecin, la pénicilline peut lui être prescrite prudemment.

Daniel voyage rarement, c'est plutôt une personne sédentaire. **Il a ses propres médecins qu'il consulte très souvent quand il en a besoin, car chacun de ces médecins connaît son dossier, ses antécédents médicaux dans de nombreux aspects comme les allergies médicamenteuses.**

Récemment, un ami de Daniel lui a parlé d'une carte d'allergie numérique, qui est une application mobile pour suivre les informations sur les allergies aux médicaments. Cette application mobile rend l'information disponible et accessible n'importe où, n'importe quand.

L'utilisation de cette application nécessite l'enregistrement les informations d'identité du patient ainsi que les détails sur les antécédents allergiques.

Cette application fournit également des conseils aux utilisateurs pour les aider à éviter les réactions allergiques et à les gérer efficacement si elles se reproduisent.

Suite à cette histoire, veuillez répondre aux questions suivantes.

Manipulation check

Suite à l'histoire que vous venez de lire diriez-vous que…

1. La réaction allergique de Daniel en 2018 était un sérieux problème de santé pour lui.
2. La réaction allergique de Daniel en 2018 lui a créé de sérieux problèmes
3. Daniel aurait peur d'avoir cette réaction allergique qu'il a eu en 2018

A votre avis…

1. Dans cette histoire, Daniel est (Sédentaire, voyageur).

Q1. Diriez-vous que...

1. Daniel a l'intention d'adopter la carte numérique d'allergies.
2. Daniel utilisera la carte numérique d'allergies.
3. Daniel prévoit d'utiliser la carte numérique d'allergies.
4. Daniel va essayer d'utiliser la carte numérique d'allergies dans sa vie quotidienne.
5. Daniel n'hésiterait pas à fournir ses informations à la carte numérique d'allergies.

Q2 : Toujours en pensant à cette histoire, diriez-vous que ...

1. Utiliser une carte numérique d'allergies pourrait améliorer le stockage des informations d'allergie de Daniel
2. Utiliser une carte numérique d'allergies pourrait améliorer l'accès de Daniel à ses informations d'allergie
3. Utiliser une carte numérique d'allergies pourrait améliorer ses rapports avec les médecins
4. Utiliser une carte numérique d'allergies pourrait améliorer sa capacité à gérer ses allergies
5. Utiliser une carte numérique d'allergies pourrait améliorer la qualité de sa prise en charge santé
6. Daniel pourrait gérer sa santé de manière plus efficace en utilisant une carte numérique d'allergie

Q3 : Si vous étiez Daniel, diriez-vous que...

1. cela me dérangerait que cette carte numérique d'allergies puisse suivre les informations me concernant.
2. je craindrais que cette carte numérique d'allergies ait trop d'informations sur moi.
3. cela me dérangerait que cette carte numérique d'allergies puisse accéder à des informations me concernant.
4. je craindrais que mes renseignements sur les allergies puissent être utilisés d'une manière que je ne pourrais pas prévoir.

Q4 : En ce qui VOUS concerne, diriez-vous que...

1. Je ne me sens pas à l'aise avec les informations que la carte d'allergie numérique me demande.
2. J'ai l'impression que cette carte d'allergie numérique recueille des renseignements très personnels à mon sujet.

3. Les informations que je fournis à cette allergie numérique sont très sensibles pour moi.

Q5 : Toujours en VOUS concernant, diriez-vous que...

1. Cette situation pourrait arriver à moi ou à mes proches.
2. Je n'ai eu aucun problème avec le réalisme de cette situation (Cette situation est réaliste ?)
3. Il est difficile pour moi de penser que cette situation est réelle Cette situation pourrait arriver ou est arrivée à mes proches ou à moi-même

Quel est votre âge?

1. 18-25 ans
2. 25-34 ans
3. 35-44 ans
4. 45-54 ans
5. Plus de 55 ans

Vous êtes?

1. Une femme
2. Un homme
3. Préférez ne pas dire
4. Autre

Quel est votre niveau d'éducation

1. Diplôme d'études secondaires ou équivalent
2. Baccalauréat ou équivalent
3. Maîtrise ou équivalent
4. Doctorat (Ph.D.) ou équivalent

Utilisez-vous des applications mobiles ?

Oui,

Non

Utilisez-vous des applications mobiles de santé?

Oui

Non

**** Avez-vous déjà fait des réactions d'allergie aux médicaments ?**

Oui, Si oui, continuez avec la question numéro +

Non

+ Cocher la réponse qui contient les symptômes de votre réaction

1. Rougeur de la peau, urticaire, gonflement de la peau qui entoure l'œil ou d'**oedèmes** sous-cutanés et/ou sous-muqueux
2. Sensation de respiration désagréable et gênante, bruit anormal émis par la respiration, respiration sifflante, nausées, vomissements, vertiges (présyncope), diaphorèse, oppression de la poitrine ou de la gorge, ou douleurs abdominales
3. Cyanose, hypotension, confusion, collapsus, incontinence ou choc anaphylactique

Suite à votre expérience, diriez vous que…

1. Votre (vos) réaction (s) était (ent) un sérieux problème de santé pour vous.
2. Votre (vos) réaction (s) vous a créé de sérieux problèmes
3. Vous aurez peur d’avoir la (les) même (s) réaction (s) allergique (s)

Appendix 4: Abstract

This thesis work was done under an industrial contract with Pikcio, a company developing a private blockchain. The initial objective was to explore several use cases of blockchain in health, based on the observation that these use cases were absent from the literature, which was dominated by descriptive studies of the potential of blockchain in health.

Based on this observation, we began our thesis by looking for use cases that we could initiate. Among those we identified, several could not be launched because of the complexity involved, and those that were started were suspended because of funding problems, lengthy procedures, and the closure of Pikcio.

This paper's thesis focuses on only one of these use cases: the digital allergy card. The four main papers and the paper in appendix 1, of which I am the sole author, allow each one to answer an aspect of our general research questions, which are: What are the ideal characteristics of a PHR that would be accepted by individuals and meet their needs for successful adoption and use? What are the elements that need to be taken into account? Would it be possible to create such an application in a scientific manner by generating rigorous and actionable knowledge?

The first paper of this thesis, which is a published chapter, focuses on the digital allergy card as a use case for blockchain in health. Through a process of action design research, we examine the relevance of blockchain by confronting its identified needs and characteristics. The reflections on this paper highlighted the importance of going deep into the analysis of the needs in the field, and the following two papers went deeper into two major challenges that were identified in the interviewees' discourses.

The second paper uses the action research framework to facilitate the adoption of the digital allergy card as a health application in the personal health record category. In this paper, we start from the observation that existing adoption models are limited to allow research results to be used by practitioners in design—for example, to consider measures to facilitate adoption in concrete projects. We use a thematic data analysis methodology inspired by grounded theory to highlight user perceptions of adoption and apply this to the digital allergy card. As a result, we were able to identify the elements of description of the content, benefits, levers, and barriers to the adoption of the digital allergy card. Some of these elements helped to inform the design of the application, and we also put forward research proposals, notably the one concerning the impact of context on the adoption of a health application.

This research proposal is the starting point for our fourth paper, which is an ongoing experimental study to investigate the adoption of health applications using the situational privacy calculus theory.

Finally, paper 3 focuses on information quality using the affordances perspective to define information quality as the result of interactions between users and the application that contains the information. This perspective allowed us to propose five design principles that were instantiated in the case of the digital allergy map.

The main limitation of our work is related to the fact that the objective of our thesis, which was to explore several use cases of blockchain in health, was not achieved because of the various difficulties we encountered. We were therefore not able to collect enough data, nor to initiate several use cases as planned. But, as a research perspective, I will start a postdoc with the objective to return to the initial objectives of the thesis by exploring, in addition to the allergy card case, the case of consent tracking for clinical studies.

Keywords: personal health records, digital allergy card, action design research, health information, blockchain, adoption.

Appendix 5 : Résumé de la thèse en français

Ce travail de thèse a été fait en contrat industriel avec Pikcio, une entreprise qui développait une blockchain privée. L'objectif initial était d'explorer plusieurs cas d'usage de la blockchain en santé partant du constat selon lequel, ces cas d'usage étaient absents de la littérature, qui était dominée par des études descriptives des potentialités de la blockchain en santé.

Nous avons commencé notre thèse par la recherche des cas d'usage que nous pourrions initier. Parmi ceux que nous avons identifié, un seul cas a pu être retenu ; celui de la carte d'allergie numérique.

Les 4 papiers principaux et le papier en annexe 1 dont je suis la seule auteure permettent de répondre chacune à un aspect de notre question de recherche générale qui est celle de savoir : Quelles sont les caractéristiques idéales d'un DPS qui serait accepté par les individus et qui répondrait à leurs besoins pour une adoption et une utilisation réussies ? Quels sont les éléments à prendre en compte ? Serait-il possible de créer une telle application de manière scientifique en faisant émerger des connaissances rigoureuses et exploitables ?

Le premier papier de cette thèse s'intéresse à la carte numérique d'allergie comme un cas d'usage de blockchain en santé. A travers un processus d'action design research, nous examinons la pertinence de la blockchain par la confrontation entre les besoins identifiés et les caractéristiques de la blockchain. Les réflexions sur ce papier ont permis de mettre en exergue l'importance d'aller en profondeur dans l'analyse des besoins de terrain et les deux papiers suivants se sont approfondis sur deux grands challenges qui ont été relevés dans les discours des interviewés.

Le deuxième papier utilise le cadre d'action design research pour faciliter l'adoption de la carte numérique d'allergie en tant qu'application de santé dans la catégorie des DPS. Dans ce papier, nous partons du constat que les modèles d'adoption existants sont limités pour permettre que les résultats de recherche soient utilisés par les praticiens lors du design pour prendre en compte des mesures afin de faciliter l'adoption dans le cadre des projets concrets. Nous utilisons une méthodologie thématique d'analyse des données inspirée de la théorisation enracinée pour faire ressortir les perceptions utilisateur relative à l'adoption et pouvoir ainsi appliquer cela dans le cas de la carte numérique d'allergie. Comme résultats, nous avons pu ressortir les éléments de description du contenu, des bénéfices, des leviers et barrières à

l’adoption de la carte numérique d’allergie. Certains de ces éléments ont permis d’informer le design de l’application et nous avons aussi émis des propositions de recherche, notamment celle concernant l’impact du contexte sur l’adoption d’une application de santé.

Cette proposition de recherche est le point de départ pour notre papier 4 qui est une étude expérimentale en cours permettant d’étudier l’adoption des applications de santé en utilisant la perspective du situational privacy calculus.

En fin notre papier 3 se focalise sur la qualité de l’information en utilisant la perspective des affordances pour définir la qualité de l’information comme le résultats des interactions entre les utilisateurs et l’application qui contient l’information. Cette perspective nous a permis de proposer cinq principes de design qui ont été appliqués au cas de la carte numérique d’allergie.

La limite principale de notre travail est liée au fait que l’objectif de thèse qui était d’explorer plusieurs cas d’usage de la blockchain en santé n’a pas été atteint à cause des différentes difficultés que nous avons rencontrés. Nous n’avons donc pas pu collecter assez de données, ni initier plusieurs cas d’usage comme prévu. Comme perspective de recherche, je vais commencer un postdoc avec pour objectif de continuer le cas de la carte d’allergie et d'initier le cas du traçage des consentements pour les études cliniques.

Mots clés : dossier personnel de santé, blockchain, carte numérique d’allergie, action design research, information de santé.

Appendix 6 : Résumé de la thèse en français chapitre par chapitre

Manuscrit 1 :

La blockchain a souvent été mentionnée ces dernières années comme étant une innovation prometteuse pour le secteur de la santé en ce qu'elle peut assurer l'échange sécurisé et la traçabilité des informations tout en respectant le cadre réglementaire de la confidentialité et de la portabilité des données de santé. Cependant, les cas concrets restent très rares dans la littérature, et nous étudions les cas d'usage pertinents appliquant la blockchain dans le domaine de la santé. Ce chapitre montre comment nous concevons une carte d'allergies basée sur la blockchain pour résoudre des problèmes concrets, à savoir l'enregistrement, le partage et la traçabilité des informations relatives aux allergies médicamenteuses. Par conséquent, nous utilisons de manière itérative la recherche de conception d'action pour déterminer les besoins, concevoir la solution, développer l'application et évaluer les résultats en impliquant les parties prenantes dans la construction et l'évaluation.

Manuscrit 2 :

L'adoption et les perceptions des utilisateurs dominent la littérature sur les dossiers de santé personnels et ont permis de mieux comprendre les comportements et les perceptions des individus quant à l'adoption des dossiers de santé personnels. Cependant, ces connaissances sont descriptives et ne sont pas exploitables pour permettre la création de dossiers de santé personnels qui surmonteront les problèmes d'adoption identifiés par les utilisateurs. Cette étude utilise la recherche par conception-action pour fournir des connaissances exploitables concernant les perceptions et l'adoption par les utilisateurs et leur application dans le cas de la carte d'allergie numérique. Pour ce faire, nous avons mené des entretiens avec des patients et des médecins dans le cadre de l'évaluation de la maquette de la carte d'allergie numérique et du premier prototype. Comme résultats, nous avons fourni quelques propositions de recherche concernant les avantages, les leviers et les obstacles à l'adoption de la carte d'allergie numérique qui peuvent être testés pour plusieurs autres dossiers de santé personnels.

Manuscrit 3 :

Malgré son importance pour la prise de décision, les études existantes sur la qualité de l'information n'abordent pas les problèmes connexes de manière concrète. Nous proposons

d'utiliser la perspective des affordances pour définir la qualité de l'information comme le résultat des interactions entre l'utilisateur et le système et d'en déduire les affordances clés qui permettent aux interactions de contribuer à la bonne qualité de l'information dans le système. Cette approche est nouvelle car elle complète d'autres études qui sont plus axées sur les cadres d'évaluation et d'analyse de la qualité de l'information. Nous avons utilisé la perspective de l'affordance dans une procédure de recherche action design et cela nous a permis de déduire 5 principes de conception qui nous permettent de répondre à notre question de recherche et qui pourraient être testés dans d'autres projets de développement d'applications mobiles ou web.

Manuscrit 4 :

Le nombre de dossiers personnels de santé (DPS) a augmenté ces dernières années. Par conséquent, la littérature s'est concentrée sur les préoccupations relatives à la confidentialité des informations de ces DSP. Alors que de nombreuses études ont souligné que ces préoccupations constituent un obstacle à l'adoption des DPS, aucune étude n'a évalué la variabilité de ces préoccupations en fonction d'autres facteurs qui peuvent les surmonter. Par conséquent, nous proposons un plan d'expérience pour mesurer l'influence des avantages perçus et des préoccupations en matière de confidentialité dans différentes situations sur l'intention d'utiliser une carte d'allergies numérique. Nous utilisons la méthode des scénarios pour un modèle à deux facteurs. Les scénarios sont construits selon la composition deux par deux entre le contexte de mobilité (voyageur versus sédentaire) et le niveau de sévérité de la réaction allergique précédente (sévère versus légère). Nous enrichirons la littérature sur l'adoption des DSP par l'identification des déterminants contextuels qui peuvent influencer l'adoption d'une carte d'allergies numérique.