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Electronic Health Record Portals in Portugal

A perspective from providers and patients

Sónia Elisa Janota Tomásio

Master Thesis presented as partial requirement for obtaining
the Master's degree in Statistics and Information
Management

NOVA Information Management School
Instituto Superior de Estatística e Gestão de Informação
Universidade Nova de Lisboa

2018

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A PERSPECTIVE FROM PROVIDERS AND PATIENTS

by

Sónia Elisa Janota Tomásio

Master Thesis presented as partial requirement for obtaining the Master's degree in Information Management, with a specialization in Knowledge Management and Business Intelligence

Co-Advisor: Professor Miguel de Castro Neto

Co-Advisor: Professor Maria Manuela Simões Aparício da Costa

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ABSTRACT

Healthcare systems are becoming more patient centered, as today's citizens are more active and more informed. In line with this trend, healthcare providers are promoting the use of online applications such as Electronic Health Record (EHR) portals. EHR portals can be defined as web based applications that combine an EHR system and a patient portal, with the potential of helping to achieve benefits for both patients and healthcare providers, which makes the adoption of EHR portals an important field to study and understand. The aim of this study is to characterize the view from providers and patients on EHR portals, having the Portuguese health system as scenario. The methodology was divided into a provider-centered and a patient-centered approach, being characterized as a mixed-methods research, as qualitative and quantitative data collection procedures were followed. Results point out that EHR portals are considered by providers crucial in the establishment of a digital relationship with patients, but efforts still need to be carried out for the users to adhere to these technologies. Also, the portals available in Portugal are heterogeneous in terms of functionalities offered, greatly differing in terms of number of functionalities. Patients view some functionalities of EHR portals more important than others and half of them are users of the portal developed by the public provider. The statistically determinants of adoption of EHR portals were verified. By having the perspective of providers and users, it was possible to provide insights that can be helpful to develop EHR portals that meet patient demands.

KEYWORDS

Open data; Health Data; Health Information Exchange; eHealth; Electronic Health Records; Electronic Health Record Portals

INDEX

1. Introduction.....	1
1.1. Background and problem identification.....	1
1.2. Research question and objectives.....	1
1.3. Study design	2
1.4. Results and contributions.....	2
1.5. Thesis structure	3
2. Literature review	4
2.1. Open data: The base concept leading the research.....	5
2.2. Health Data: From open data to Health Information Exchange	16
2.2.1. EHRs: key systems in health informatics.....	19
2.2.2. From local records to electronic exchange of data: the rise of health information exchange	23
2.2.3. Putting the patients in the equation: EHRs leading the way to EHR Portals	25
2.3. The Portuguese health system: characterization and the potential role of EHR portals	27
3. Methodology	31
3.1. Provider-Centered approach.....	33
3.1.1. Study 1: Description of providers' view on EHR portals	33
3.1.2. Study 2: Comparative analysis of EHR portals' functionalities	34
3.2. Patient-Centered approach.....	36
3.2.1. Study 3: Characterization of patient adoption of EHR Portals.....	36
4. Results and discussion	39
4.1. Provider-Centered approach.....	39
4.1.1. Study 1: Description of providers' view on EHR portals	39
4.1.2. Study 2: Comparative analysis of EHR portals' functionalities	45
4.2. Patient-Centered approach.....	51
4.2.1. Study 3: Characterization of patient adoption of EHR Portals.....	51
5. Conclusions, limitations and recommendations for future works.....	59
6. References.....	61
Appendix A.....	66
Structure of the open-ended interview designed for study 1.....	66
Transcript of the interview to the President of SPMS.....	66
Appendix B: Questionnaire items.....	70

LIST OF FIGURES

Figure 2.1 - Researched areas	4
Figure 3.1 - Research methodology used for each study.....	32
Figure 4.1 - <i>Word Cloud</i> of interview transcript	45
Figure 4.2 - Research model used verified, adapted from the new research model based on the unified theory of acceptance and use of technology in a consumer context (UTAUT2) (Tavares et al., 2018; Tavares & Oliveira, 2014, 2016, 2017)	52
Figure 4.3 - Results for variable “Knowledge of EHR portals”	54
Figure 4.4 - Results for variable “Most important functionalities”	56
Figure 4.5 - Structural model	58

LIST OF TABLES

Table 2.1 - Papers reviewed related to Open Data	5
Table 2.2 - Summary of Panton Principles (Molloy, 2011).....	7
Table 2.3 - Benefits of open data (Janssen et al., 2012)	10
Table 2.4 - Barriers of open data (Janssen et al., 2012).....	12
Table 2.5 - Papers reviewed related to health data.....	16
Table 2.6 - Data Stewardship Principles (Bloomrosen & Detmer, 2008).....	19
Table 2.7 - Types of Clinical Data Repositories (Wade, 2014)	20
Table 2.8 - EHRs Technical Requirements.....	21
Table 2.9 - Phases of HIE Assimilation (Esmailzadeh & Sambasivan, 2016)	25
Table 2.10 - Overview of the definitions and differences between main concepts related to EHRs (Cruz-Cunha et al., 2016).....	26
Table 2.11 - Papers Reviewed Related to Portuguese health system	27
Table 3.1 - Overview of objectives, data collection methods and studies	31
Table 3.2 - Summary of Providers Contacted	34
Table 3.3 - Potential functionalities of EHR Portals (Pagliari et al., 2007)	35
Table 3.4 - Correspondence of providers approached in Study 1 and EHR portals analyzed in Study 2.....	36
Table 4.1 - Interview results.....	39
Table 4.2 - Results Observed for the Portals for Functionalities “Access to provider's EHR” and “Personal health organizer”	46
Table 4.3 - Results observed for the portals for functionalities “Self-management support” and “Communication”	47
Table 4.4 - Results Observed for the Portals for Functionalities “Information Repository” and “Sources of support”	49
Table 4.5 - Results Observed for the Portals for Functionality “Capture of symptoms or health behavior data”.....	49
Table 4.6 - Sample characteristics for variable “Age”	52
Table 4.7 - Sample characteristics for variable “Gender”	53
Table 4.8 - Sample characteristics for variable “Education”	53
Table 4.9 - Sample characteristics for variable “Chronic illness/disability”	53
Table 4.10 - Results for variable “EHR portals in use”	55
Table 4.11 - Cronbach’s alpha, composite reliability, and average variance extracted	57
Table 4.12 - Cross Loadings	57
Table 4.13 - Summary of findings regarding hypotheses.....	58

LIST OF ABBREVIATIONS AND ACRONYMS

DSRM	Design science research methodology
EHR	Electronic Health Record
HIE	Health Information Exchange
HITECH	Health Information Technology for Economic and Clinical Health
ICT	Information and Communication Technologies
N/A	Not applicable
NHS	National Health Service
PLS	Partial least squares
SEM	Structural equation modelling
SPMS	Serviços Partilhados do Ministério da Saúde
UTAUT2	Extended unified theory of acceptance and usage technology

1. INTRODUCTION

1.1. BACKGROUND AND PROBLEM IDENTIFICATION

For some years now, health data is being produced in ever-increasing amounts (Khan & Hoque, 2016). Whether from medical systems, mobile devices, wearables or sensors, healthcare has become more digital and data-driven (Khan & Hoque, 2016; Kostkova et al., 2016). Such phenomenon has greatly contributed to the momentum around the application of information and communication technologies (ICT) in healthcare, both nationally and internationally (Angst & Agarwal, 2009). One of the most transformational application of ICTs to healthcare was on patient's medical records (Khan & Hoque, 2016). These have become increasingly digital, in the form of Electronic Health Records (EHRs) (Khan & Hoque, 2016) and viewed by many as the foundation for a safer and more efficient healthcare system (Angst & Agarwal, 2009).

This research focuses on the patient-directed side of EHR technologies: EHR portals. These are web-based applications that combine an EHR system and a patient portal (Cruz-Cunha, Miranda, Martinho, & Rijo, 2016; Tavares & Oliveira, 2017). Among the reported benefits of EHR portals are the access and visibility given to patients over their own health records (Angst & Agarwal, 2009) and the improvement of efficiency to healthcare providers (Angst & Agarwal, 2009; Costa, Aparício, & Figueiredo, 2012; Tavares & Oliveira, 2014). This research has as scenario Portugal, which health system comprises three co-existing and overlapping systems – public, private and subsystems - and a multiplicity of providers (Barros, Machado, & Simoes Jde, 2011; De Almeida, Gonçalo, Augusto, Fronteira, & Hernández-Quevedo, 2017). Having faced a severe austerity program, with significant impact on healthcare sector (De Almeida et al., 2017; Tavares & Oliveira, 2014), EHR portals assume particular relevance as to relief the Ministry of Health budget (Tavares & Oliveira, 2014). Despite of an e-governmental strategy, Portugal still lags behind other European countries in terms of use of internet for health purposes (Tavares & Oliveira, 2014) and only 7% of the population uses EHR portals (Tavares & Oliveira, 2017).

Under the assumption that EHR portals are desirable technologies (Angst & Agarwal, 2009), it is important to understand its adoption (Angst & Agarwal, 2009; Tavares, Goulão, & Oliveira, 2018; Tavares & Oliveira, 2014, 2016, 2017). However, there are many examples in the literature of information technologies that were taken as promising but failed to succeed due to resistance by some of the stakeholders (Angst & Agarwal, 2009). Thus, having the perspective from both providers and patients on EHR portals was identified as a relevant approach to pursue. Nevertheless, it is worth to emphasize that there are more stakeholders of EHR portals than just healthcare providers and patients (Costa et al., 2012) but, for this research, efforts are concentrated in these two groups.

1.2. RESEARCH QUESTION AND OBJECTIVES

Having this scenario as background, the research question that guides the research was: *What is the view from providers and patients on EHR portals in Portugal?*

Starting off with this question, the main goal was established to be the characterization of the use of EHR portals in Portugal. As vast and disperse this objective may present itself, it is crucial to delineate specific and objective goals to achieve, proposes as being:

- (1) To characterize the point of view of healthcare providers on EHR portals;

- (2) To identify the functionalities of the EHR portals available in Portugal;
- (3) To identify the EHR portals patients are using and the functionalities they find more important;
- (4) To verify the determinants of adoption of EHR portals.

1.3. STUDY DESIGN

The overall methodological design can be classified as a mixed-methods research, as more than one data collection method was adopted (Tashakkori & Creswell, 2007). Considering the dichotomy of healthcare providers and patients understated in the research question, the methodological approach was split into two blocks: a *provider-centered* approach and a *patient-centered* approach.

On the *provider-centered* approach the first two objectives were addressed: (1) to characterize the point of view of healthcare providers on EHR portals and (2) to identify the functionalities of the EHR portals available in Portugal. The first objective was addressed by gathering information from providers on EHR portals current state and potential developments and the data collection method was the qualitative design of interviews. The design to achieve objective (1) led to *study 1: description of providers' view on EHR portals*. The second objective was achieved by comparing the functionalities offered by EHR portals with the ones described in literature. The type of data collected was qualitative and it followed a design science research methodology. The EHR portals were evaluated in terms of functionalities, which was consubstantiated in *study 2: comparative analysis of EHR portals functionalities*.

As part of the *patient-centered* approach the remaining objectives were addressed: (3) to identify the EHR portals patients are using and the functionalities they find more important and (4) to verify the determinants of adoption of EHR portals. Both objectives were converged in the same study: *study 3: characterization of patient adoption of EHR Portals*. The data collection method was quantitative, and the instrument used was a questionnaire. The research methodology adopted was natural science: as discovery activity objective (3) was addressed and as justification activity objective (4) was attained.

1.4. RESULTS AND CONTRIBUTIONS

With study 1, insights from the public provider were obtained on its own-developed EHR portal. Several barriers were indicated as posing in the way of information systems' development; whether technical, financial or privacy-related, many challenges are ahead of the national health service (NHS) in terms of digital transformation, and the EHR portal is one side of it. Nevertheless, the goal is to have all the Portuguese population subscribing the portal, regardless of age. For that, several efforts are being carried out but success will require the intervention of civil society as a whole. The socio-economic context of Portugal as having an aged population and high healthcare expenditure (Barros et al., 2011; De Almeida et al., 2017) should be viewed as a driving force towards the development of eHealth strategies, rather than a barrier. A relevant contribution of this study was that EHR portals ought to be viewed not just as an application but as the base for the digital relationship between the NHS and patients. Providers representing the other systems of the Portuguese health system were contacted likewise, but interviews were not made.

In study 2, results pointed out that none of the EHR portals analyzed presented all the functionalities suggested in the literature but also none failed to present at least one functionality. NHS' portal was

considered the most complete and versatile portal among the ones analyzed, as demonstrated higher number of functionalities. Also, some functionalities such as having a clinical agenda and allowing to book appointments online were present on most of the portals analyzed, hinting that these are considered the most important to providers. On the other hand, there are functionalities that the majority of the portals selected did not comprise. A relevant contribution of this study was to assess how each portal performs when compared to competitors but also to allow patients the visibility of which ones better suit their expectations.

At last, in study 3, the results obtained indicated that most users qualify themselves as having a median knowledge on EHR portals and that almost half the sample were already subscribers of NHS' portal. The portals from private providers and subsystem registered significantly less users. Another goal of this study was to identify the functionalities patients find more important on EHR portals, with results indicating that accessing the provider's EHR (includes viewing clinical history, test results and medication) and communicating with the provider (includes booking appointments, reordering prescriptions and seeking advice) were considered the most important. Finally in this study, the statistically significant determinants of technology use were verified to be habit and behavioral intention and the determinants of behavioral intention were performance expectancy and habit. The results of this study have the potential to provide managerial insights that can be helpful to providers when designing EHR portals that engage and satisfy digital-prone patients.

1.5. THESIS STRUCTURE

The organization of the document follows the nominal, most commonly used, structure of an empirical research work, which fits the scope of the field of research and the process undertaken.

It is divided into six chapters in total. On the first one - Introduction - it is presented the theme of the research work and its context and relevance. It will also highlighted the objectives proposed to be accomplished and the main contributions expected to be provided with this research. On the second chapter - Literature review-, it is presented the critical literature review carried out throughout the time of the research, having as target a multidisciplinary approach of the problem. On chapter number three - Methodology- it is explained the methodology applied in the empirical phase, contextualizing its steps and theoretically justifying its applicability, in the scope of the research fields. Following it up, on the fourth chapter - Results and discussion - there is the presentation of the results of the research, as well as the critical discussion of them. Towards the end, on chapter five – Conclusions, limitations and recommendations for future research works - the main conclusions of the thesis are proposed, giving an answer to the research question and assessing the achievement of the objectives previously established. In that chapter are also presented the most relevant insights from the empirical study that may inspire new research endeavors in upcoming years, also pointing out the limitations to the present work. Lastly, the references relied on and the appendices that provide supplementary information to be considered for the research are exhibited - chapter six.

2. LITERATURE REVIEW

In this chapter the efforts were channeled to studying the state-of-the-art. The main objective of the literature review was to understand how the subjects that compose the research question have been studied.

For that, it was implemented a concept-centric approach to search and structure the review, as suggested by Webster and Watson (2002). Online available resources were relied on to retrieve the most important scientific papers for the scope of research, namely the search engine *Google Scholar*[®] and open source repositories as *RCAAP Scientific Open Access Repository of Portugal*, *B-ON - Online knowledge library*, the *Open Science Repository*, *RUN-Nova University Repository* and *PubMed - US National Library of Medicine National Institutes of Health*.

The papers were searched by keywords and expressions identified as relevant for the research question. The rationale for the definition of such search criteria was the deconstruction of the problem into its multi-disciplinary parts, as shown in Figure 2.1. These are the pillar research fields for the research, to the extent that the question overlaps knowledge from these four broad areas. For schematization and perception purposes, these fields of science were subject to detailed reflection in the upcoming sub-chapters and the most relevant papers are identified in tables by the year, the author(s) name, the name of the publication, the title and the keywords. It must be emphasized that the research started from broader concepts as *open data*, *health data*, *health information exchange* and *electronic health records*, among others, and was consecutively narrowed down to more specific key expressions as *electronic health record portals*, *electronic health record technologies* and *eHealth*. Because the research has Portugal as scenario, papers on the characterization of the Portuguese health system were also searched at this stage, using as key expression *Portugal health system*, in order to frame EHR portals in it.

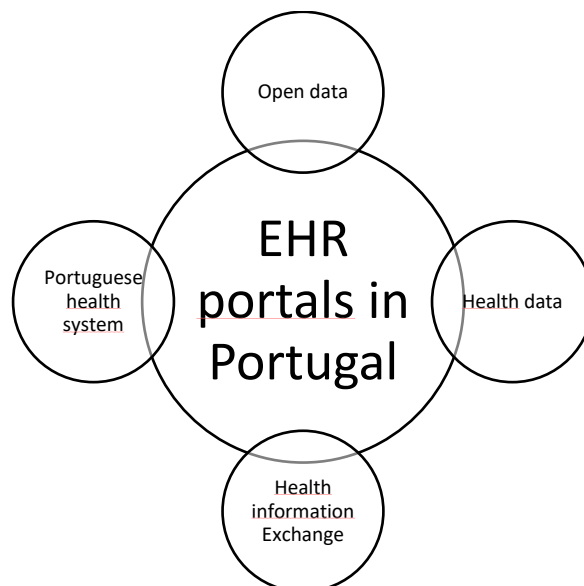


Figure 2.1 - Researched areas

Finally, worth to be noted still in this scope, that the critical literature review was carried out throughout the entire research period and not only at its starting point; a rather significant amount of

research work in these fields is constantly being published, especially related to electronic health records and to health information exchange and its contributions as knowledge-creating outputs were considered until the closing of this research.

2.1. OPEN DATA: THE BASE CONCEPT LEADING THE RESEARCH

The review was initiated by revising the concept that transverses the research: *open data*. On the agenda was not only the definition of the concept but also the analysis of its potential evolution and the current state of development. To be noted that, at this first literature review endeavor, open data started to be searched as a broader concept and only afterwards the search was drilled down to its application in healthcare; the refinement of the concepts was done as knowledge-consolidation strengthened. Summarizing the most relevant insights obtained, ideas were structured by first analyzing the concept definition that mostly fits the purpose. Following up, the types of open data were identified and then the current state and expected developments for upcoming years were addressed. The benefits, barriers and myths about open data were also highlighted. At last, it is exemplified some case-studies in the field, with the objective of giving a practical framework to the theoretical concept and to compare strategies from different countries. Table 2.1 presents the most relevant papers relied on at this stage.

Table 2.1 - Papers reviewed related to Open Data

Year	Author(s)	Publication	Title	Keywords
2008	Murray-Rust, P.	Serials Review	Open Data in Science	N/A
2011	Molloy, J. C.	PLoS Biology	The Open Knowledge Foundation: Open Data Means Better Science	N/A
2011	Huijboom, N., Van den Broek, T.	European Journal of ePractice	Open data: an international comparison of strategies	E-Government, open data, transparency of government
2012	Janssen, M., Charalabidis, Y., Zuiderwijk, A.	Journal Information Systems Management	Benefits, Adoption Barriers and Myths of Open Data and Open Government	Systems theory, institutional theory, adoption, diffusion, open data, open government, governance, transformation
2014	Meije, R., Conradie, P., Choenni, S.	Journal of Theoretical and Applied Electronic Commerce Research	Reconciling Contradictions of Open Data Regarding Transparency, Privacy, Security and Trust	Open data, Precommirment, Transparency, Privacy, Security, Trust
2014	Conradie, P., Choenni, S.	Government Information Quarterly journal	On the barriers for local government releasing open data	Open data, PSI, Process barriers, Data release

2015	Hossain, M., A., Dwivedi, Y. K., Rana, N. P.	Journal of Organizational Computing and Electronic Commerce	State-of-the-art in open data research: Insights from existing literature and a research agenda	Literature review, open data, open government data, research agenda
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Note. N/A = Not applicable

Defining the concept was a matter addressed by several authors in the past years. Back in 2012, some authors defined open data as the “non-privacy-restricted and non-confidential data which is produced with public money and is made available without any restrictions” (Janssen, Charalabidis, & Zuiderwijk, 2012, p. 258). Other authors gave a broader definition to the concept, as a “philosophy or strategy that encourages mostly public organizations to release objective, factual, and nonperson-specific data that are generated or collected through the delivery of public services, to anyone, with a possibility of further operation and integration without any copyright restrictions” (Hossain, Dwivedi, & Rana, 2016, p. 14). It can be withheld from these two definitions that, though not the same, they are complementary with regards to the following assumptions: (1) having non-restricted access to data subject to being further used, (2) the origin of the data being the public sector and (3) data being non-confidential. From the second common insight, it can be noticed that open data was strictly linked to public domain, which may then constitute a constraint for applying the concept to healthcare in the sense that, in Portugal, this sector relies on public and private providers (Barros et al., 2011). Regarding the third common assumption, it can be said that another challenge imposes to healthcare sector; as a sector that mostly records private and confidential data, may it still be possible to equate making data available? Later in this literature review this question is to be recopied, when the barriers for open data are resumed. Not only because of its detailed definition but also because they are broadly quoted in other relevant research studies in the field, these definitions are both considered as the benchmark for open data concept-definition in the context of this study (Hossain et al., 2016; Janssen et al., 2012). To be highlighted the assumption that both these definitions are not contradictory but in fact complementary, hence considering both relevant for this research.

Having defined the concept of open data that will inherently be present throughout the study, a closer look is taken on the types of data. According to Hossain et al. (2016), there are various possible categorizations for open data: primary or secondary, real-time or offline, location-based or generic reports, maps, satellite photographs, pictures and paintings, the genome, medical data, scientific formula, among others. The most important fact to be retained for the purpose of this research is that the authors specifically identify medical data as one of the types of open data. This categorization is an important contribute to the research in such a way that provides the theoretical justification and context for addressing open data in the healthcare context (Hossain et al., 2016).

Following this characterization of the concept *per se*, it is worth to consolidate what is the current state in the research of open data and its applicability. In the late 2000's and early 2010's, the theme was addressed by authors mostly as a theoretical phenomenon that could greatly contribute to science progress and to a knowledge-founded society (Molloy, 2011; Murray-Rust, 2008). This is justified by the fact that science would be nothing without data; its collection, analysis, publication, critique and reuse is built on data and the more it is openly available, the more efficient and reproducible the scientific process becomes (Molloy, 2011). Both Murray-Rust (2008) and Molloy, (2011) experienced the difficulty of not having fellow researchers sharing data. Barriers included inability to access data,

restrictions on usage applied by publishers or data providers, and publication of data difficult to be reused (Molloy, 2011). Likewise, Murray-Rust (2008) emphasizes the extreme value of data reuse and details practical examples of it. Under this scenario, at the beginning of the decade, a major movement was created to reform the process of scientific communication - the *Open Knowledge Foundation* (Molloy, 2011). United by the same organizational values and principles, the Open Knowledge Foundation was established to promote open knowledge and came to life to respond to the barriers previously mentioned (Molloy, 2011). It has since included an international community of scientists from different backgrounds working as a single entity with the purpose of developing guidelines, tools and applications to promote open data initiatives (Molloy, 2011). In order to reduce the installed confusion on how to address open data, the Open Knowledge Foundation launched, in 2010, a new set of principles - the *Panton Principles for Open Data in Science* (see Table 2.2). The epitome of the principles was that all data, with very few exceptions, should explicitly be placed in the public domain (Molloy, 2011). These principles, along with other initiatives, contributed to the momentum for the launch of the open data movement in science and are referred today as a milestone for the way science community engaged on open data (Molloy, 2011).

Table 2.2 - Summary of Panton Principles (Molloy, 2011)

Panton Principles	
1	When publishing data, make an explicit and robust statement of your wishes
2	Use a recognized copyright waiver or license that is appropriate for data
3	If you want your data to be effectively used and added to by others, it should be open as defined by the Open Knowledge/Data Definition-in particular, non-commercial and other restrictive clauses should not be used
4	Explicit dedication of data underlying published science into the public domain s strongly recommended and ensures compliance with both the Science Commons Protocol for Implementing Open Access Data and the Open Knowledge/Data Definition.

One of the challenges of this movement was to encourage unwillingly scientists to share their data, whom faced fear of exploitation and lack of recognition for the work performed (Molloy, 2011). Helping to solidify the pillars of the open data movement was the outburst of worldwide web and new collaborative tools, both being phenomena that reshaped society as a whole (Molloy, 2011). Via these two highly cited papers, it can be realized that science community was historically conservative when it came to sharing data (Molloy, 2011; Murray-Rust, 2008). Also, to be pointed out that this movement is recent, starting to have scientific attention only in the beginning of this decade, judging by the number of published papers found that date from last decade.

Open data, as a field of science, was then at early stage of development but from the analysis of the works of Murray-Rust (2008) and Molloy (2011) a unison view of what is open data remains unachieved; if on the one hand Molloy (2011) insights on the concept and on the broad, abstract use of open data, on the other hand, Murray-Rust (2008) exemplifies its application with practical examples. Despite the initial reluctance faced, open data began to raise scientific debate as society moved towards being knowledge-based and as mobile networking and the Internet of Things raised prominence (Hossain et al., 2016).

Likewise, the subject started to appear on government agendas last decade; from the *United Kingdom Research Councils* to the *United States National Institutes of Health*, passing by the *European Commission*, all exercised pressure to move towards an open data paradigm in science (Molloy, 2011). What is more, the concept received notoriety when then President of the United States Barack Obama brought it to public domain in 2009, followed by British governmental initiatives on transparency in 2011 (Hossain et al., 2016). Despite having been announced that the United States would embrace an unprecedented level of openness in government, debate goes on as still after this strategy coming to light, US government still spends four times more on securing data than on opening it up (Huijboom & Broek, 2011). It can be argued then that much more is to be done by governments to make results meet proclaimed objectives (Huijboom & Broek, 2011). Several other countries have followed the United States by adopting open data policies and placing government transparency in the agenda of politicians and policy-makers (Huijboom & Broek, 2011). Some of them have actually decreed the availability of data with no copyright obligations, making it possible to be reused and recombined and its importance is gradually being acknowledged by researchers (Hossain et al., 2016). Australia, Denmark and Spain are only a few examples of countries which stated the motivation on open data and established programs for that purpose (Huijboom & Broek, 2011). Interesting to be noted though that the focus of the strategic plans vary among these countries which indicates that, despite consensually acknowledging the importance of open data, the motivations behind its implementation differ upon socio-economical context (Huijboom & Broek, 2011). Naming some examples, whereas the United Kingdom specifically stresses the importance of open data to strengthen law enforcement, Spain highlights its potential to develop new products and services (Huijboom & Broek, 2011). At the same time, Denmark, for instance, focuses on the opportunities for information and communication technologies (ICT) companies and for citizens seeking ideas and solutions for their everyday problems (Huijboom & Broek, 2011). Questing to compare the strategies of different countries, Huijboom and Van den Broek identified back in 2011 three main motivations in the respective programs: (1) to increase the democratic and political participation, (2) to foment the development of the products and services and (3) to strengthen law enforcement. These different strategic goals are relevant to be pointed out not only from a political point of view but also as a demonstration of the many fields of applicability of open data and its potential contributions to modern societies. Likewise, Huijboom and Van den Broek (2011) also studied the instruments applied by five countries that serve as examples of advanced information societies (Australia, Denmark, Spain, United Kingdom and United States) and concluded they can be categorized in four types: (1) education and training, (2) voluntary approaches, (3) economic instruments and (4) legislation and control. Two major insights can be taken out from the study; if on the one hand each country applies at least one instrument of each category, on the other hand, the level of detail of the strategies is clearly different between countries (Huijboom & Broek, 2011). At last, to be referred that the researches made demonstrate that, despite the growing establishment of open data policies and strategies, governmental organizations are still close-minded and not prone to disclosing information, fearing it could raise public criticism over the political information exposed (Huijboom & Broek, 2011). In Portugal, a census made in 2016 for the 308 Portuguese municipalities showed that open data is still seen more as a fulfillment of legal obligations than as an opportunity to increase the credibility of public administration and introduce new business opportunities (Neto, Rego, Neves, & Cartaxo, 2017).

It can be concluded, from the several papers consulted, that due to being a relatively new concept and area of expertise, open data faces the challenge of needing more case studies of implementation

practices, as governments still lack understanding of the effects of an open data approach (Huijboom & Broek, 2011). In the scientific community similar situation happens; it has been noticed that more knowledge is needed to assess the impacts of open data (Hossain et al., 2016). What is more, the case studies presented in literature are very much linked to governmental initiatives, contributing to link the concepts of open data and open government tightly (Huijboom & Broek, 2011; Janssen et al., 2012).

Nevertheless, worth to be highlighted that, although most open data initiatives are in the scope of public sector, its concept started to be applied to private sector more recently (Hossain et al., 2016). This view represents a shift from what was initially defined as open data and previously in this chapter described; from a public-only originated data, a shift can be witnessed to the idea that any business entity, regardless of being public or private, can add value with an open data approach. Given this evolution in the applicability, open data was defined by Meijer, Conradie and Choenni (2014) as “the data that is not traceable to a person, with the aim to be reused and redistributed by everyone, without restrictions from copyright, patents or other mechanisms of control” (p. 33), thus not putting in the equation the origin of the data and broadening the concept of open data. This represents a step away from the notion that open data is a governmental-exclusive affair and expanding its perimeter to private organizations (Meijer et al., 2014). This is as relevant for the research as it understates that one can discuss open data in the healthcare system regardless of its origin as public or private, thus potentially broadening the scope of the research question to public and private healthcare providers.

In the quest for a deep understanding of the breakthrough of open data and how does it serve modern society, it is relevant to assess how balanced is the scale when the advantages and disadvantages are weighted in; because the pretense holistic approach of this research aims to critically address the existing framework, barriers and benefits ought to be considered. By conducting a series of interviews Janssen et al. (2012) went beyond the identification of benefits and barriers of open data, having identified inclusively the myths associated to it.

Starting off with the benefits, the central role is played by the argument that open data creates more value than the economic exploitation of data (Janssen et al., 2012). What is more, the adoption of open data policies stimulate innovation, economic growth and citizen satisfaction (Janssen et al., 2012). Much like the work of Huijboom and Van den Broek (2011), Janssen et al. (2012) also stress out the importance of open data in a policy-making context. It is pointed out that policy-makers should share data if aiming to assess the correctness and veracity of the policies (Janssen et al., 2012). But the opportunities for open data should not be resumed to governmental affairs, as its use in the private sector is a chance for companies to reach more customers and to develop better relationships with them (Hossain et al., 2016). Interestingly, interviewees by Janssen et al. (2012) viewed sharing data as a social value, much like an altruistic and transparent measure that advances knowledge creation.

Another concept brought to the table in the scope of open data is collective intelligence; the underlined idea that a group of individuals reach better solutions than the smartest of people on their own will only be possible with the sharing of data with no barriers (Janssen et al., 2012). A relevant example of this phenomena in healthcare is the web page *Patients Like Me*, an eHealth platform which connects people with similar clinical symptoms so they can share experiences and information (Hossain et al., 2016).

In a field of applicability previously in this chapter discussed - academic research - open data could contribute to reduce duplicated and redundant research work, thus contributing to the optimization of resources (Hossain et al., 2016). Moreover, sharing data can be viewed as a means of validating and comparing research results, thus fastening the scientific progress (Hossain et al., 2016). Finally in what benefits are concerned, Janssen et al. (2012) proposed to group them in three categories: (1) political and social, (2) economic and (3) operational and technical, being the political and social identified by the authors as the most important category. Besides the ones already here dissected, Table 2.3 further identifies the most relevant benefits according to Janssen et al. (2012).

Table 2.3 - Benefits of open data (Janssen et al., 2012)

Category	Benefits
Political and Social	More transparency
	Democratic accountability
	More participation and self-empowerment of citizens (users)
	Creation of trust in government
	Public engagement
	Scrutiny of data
	Equal access to data
	New governmental services for citizens
	Improvement of citizen services
	Improvement of citizen satisfaction
	Improvement of policy-making processes
	More visibility for the data provider
	Stimulation of knowledge developments
Creation of new insights in the public sector	
New (innovative) social services.	
Economic	Economic growth and stimulation of competitiveness
	Stimulation of innovation
	Contribution toward the improvement of processes, products, and/or services
	Development of new products and services
	Use of the wisdom of the crowds
Creation of a new sector adding value to the economy	
Availability of information for investors and companies	
Operational and Technical	Optimization of administrative processes
	Improvement of public policies
	Access to external problem-solving capacity
	Fair decision-making by enabling comparison
	Easier access to data and discovery of data
	Creation of new data based on combining data
	External quality checks of data (validation)
Sustainability of data (no data loss)	
The ability to merge, integrate, and mesh public and private data	

Despite the relatively extensive and diverse list of benefits, Hossain et al. (2016) reinforce that the high expectations for open data are still mostly theoretical and a practical framework lacks being realized. The same authors argue though that further research is needed as to get more quantitative evidence. Thus, it can be retained that the lack of a quantitative approach ought to be attributed to the fact that scientific research on open data is still at its beginnings and not so much because open data is not dotted of such valence.

Moving on to discuss the barriers of open data, for simplification of presentation, they were attributed the same meaning of challenges, impediments or risks, same as in the consulted literature (Hossain et al., 2016). To ease understanding, the identified barriers can be grouped into four categories (Hossain et al., 2016).

The first, by no order of importance, being the institutional barriers which are often associated to organizations and society (Hossain et al., 2016). The main impediment in this category is related to management affairs and resources, as per the literature; lack of knowledge by the leaders and a risk-avoidance approach compose the picture (Hossain et al., 2016). Standing before such reality, the fear of losing control over data surpasses entrepreneurship endeavors (Hossain et al., 2016; Janssen et al., 2012). Therefore, sharing data is not often a priority for organizations as the incentives and outcomes are not yet clear (Hossain et al., 2016). What is more, opening data requires a set of extensive resources and propitious environment with regards to financial, technical and human resources (Hossain et al., 2016). To sum up this category, weighting in the equation of open data adoption is a risk-averse culture (Janssen et al., 2012) and the fact that its added value is not yet well defined (Hossain et al., 2016).

Secondly in the category of barriers are the legal aspects. These correspond mainly to privacy and security-related matters; substantially in the agenda in past years, privacy still raises concern despite significantly relying on sophisticated technological solutions as anonymization and encryption of data (Hossain et al., 2016). This transversal concern stated in the literature regarding data privacy, transparency and accountability in the scope of open data provides the theoretical justification for the research work as addressing the concern for information privacy in healthcare is something brought to the agenda later in the research. What is more, the legal barriers are not resumed to these and ownership, contract/agreement, copyright and licensing issues also contribute to it (Hossain et al., 2016). Despite the broadly-identified need to make the use of data less restrictive, the right to control data keeps being much centralized in its creator so the concept of property applied to data is still much of a reality (Hossain et al., 2016). Nevertheless, a legal framework oriented towards licensing restrictions is important as to provide the rules of use and reuse of data (Hossain et al., 2016). Actually, that would be the way to make sure opened datasets are used for the established purposes and that sincere intentions are met (Hossain et al., 2016).

Third in line with respect to barriers are the technological. To begin contextualizing, managing data is considered a complex and demanding task in terms of technological infrastructure (Hossain et al., 2016; Janssen et al., 2012). Incapable of complying with anonymization requirements, organizations choose not to disclose data or do disclose it in unstructured and unprocessed form, making it unsuitable to be reused (Hossain et al., 2016). Indeed, the quality of data takes the leading role as one of the major barriers according to Hossain et al. (2016), comprising incompleteness, obsolescence, redundancy and inconsistency of data. Some authors go beyond this and claim that having poor quality of data is the same as having no data in the sense that data impossible to reuse has no value at all

(Conradie & Choenni, 2014). Still to what technological impediments are concerned, accessibility plays an important role; contents that are not linked nor indexed are not likely to be searchable (Hossain et al., 2016). Further to that, standardization of data is not a common practice which makes technically challenging to integrate data from different formats and platforms (Hossain et al., 2016). A major concern raised by some studies, compatibility-oriented efforts urge to be made if aiming for the success of open data initiatives (Hossain et al., 2016).

Lastly, the economic barriers are the least studied among the four categories but should not be neglected (Hossain et al., 2016; Janssen et al., 2012). At the top of the list in this type of barriers are, as intuitive as it goes, its costly adoption (Hossain et al., 2016). The necessary infrastructure and the technical skills for opening, updating and maintaining datasets is an expensive resource that may discourage organizations to give priority to its implementation, due to not having financial availability (Hossain et al., 2016). Another highlighted reason is that most organizations base their revenue system in the income they get from data (Janssen et al., 2012). Thus, the loss of a substantial share of their income along with the expense associated to meeting technical requirements are two heavy impediments on open data adoption (Hossain et al., 2016; Janssen et al., 2012).

To be noted that this categorization in four types, proposed by Hossain et al. (2016), was hereby discussed as meeting the purpose of debating the main barriers of open data. Nevertheless, authors like Janssen et al. (2012) go further when analysing it, suggesting a categorization into more specific areas and comprising all the identified barriers in the literature, as of 2012. What is more, all subsequent researches, by Hossain et al. (2016) inclusively, cite this in-depth analysis when doing systematic reviews of the literature. Thus, on Table 2.4 it is presented some of the barriers identified by Janssen et al., (2012), anticipated to be relevant when addressing the challenge of health information exchange in the Portuguese healthcare system. To be at last mentioned that the barriers presented are interrelated and hardly a single one of them is verified alone (Janssen et al., 2012). This is a relevant insight in the sense that several barriers are to be faced when approaching open data initiatives and that when contextualizing it with the healthcare sector, their interrelatedness should not be neglected (Janssen et al., 2012).

Table 2.4 - Barriers of open data (Janssen et al., 2012)

Category	Barriers
Institutional	Emphasis of barriers and neglect of opportunities
	Unclear trade-off between public values (transparency vs. privacy values)
	Risk-averse culture (no entrepreneurship)
	No uniform policy for publicizing data
	Making public only non-value-adding data
	No resources with which to publicize data (especially small agencies)
	Revenue system is based on creating income from data
	Fostering local organizations' interests at the expense of citizen interests
No process for dealing with user input	
Task complexity	Debatable quality of user input
	Lack of ability to discover the appropriate data
	No access to the original data (only processed data)

	<p>No explanation of the meaning of data</p> <p>No information about the quality of the open data (see category "Information Quality")</p> <p>Apps hiding the complexity but also potential other use of open data</p> <p>Duplication of data, data available in various forms, or before/after processing resulting in discussions about what the source is</p> <p>Difficulty in searching and browsing due to no index or other means to ensure easy search for finding the right data</p> <p>Even if data can be found, users might not be aware of its potential uses</p> <p>Data formats and datasets are too complex to handle and use easily</p> <p>No tooling support or helpdesk</p> <p>Focus is on making use of single datasets, whereas the real value might come from combining various datasets</p> <p>Contradicting outcomes based on the use of the same data</p> <p>Invalid conclusions</p>
Use and participation	<p>No incentives for the users</p> <p>Public organizations do not react to user input</p> <p>Frustration at the existence of too many data initiatives</p> <p>No time to delve into the details, or no time at all</p> <p>Having to pay a fee for the data</p> <p>Registration required before being able to download the data</p> <p>Unexpected escalated costs</p> <p>No time to make use of the open data</p> <p>Lack of knowledge to make use of or to make sense of data Lack of the necessary capability to use the information</p> <p>No statistical knowledge or understanding of the potential and limitations of statistics</p> <p>Threat of lawsuits or other violations</p>
Legislation	<p>Privacy violation</p> <p>Security</p> <p>No license for using data</p> <p>Limited conditions for using data</p> <p>Dispute and litigations</p> <p>Prior written permission required to gain access to and reproduce data</p> <p>Reuse of contracts/agreements</p>
Information Quality	<p>Lack of information</p> <p>Lack of accuracy of the information</p> <p>Incomplete information, only part of the total picture shown or only a certain range</p> <p>Obsolete and non-valid data</p> <p>Unclear value: information may appear to be irrelevant or benign when viewed in isolation, but when linked and analyzed collectively it can result in new insights</p> <p>Too much information to process and not sure what to look at</p>

	Essential information is missing
	Similar data stored in different systems yields different results
Technical	<p>Data must be in a well-defined format that is easily accessible: while the format of data is arbitrary, the format of data definitions needs to be rigorously defined</p> <p>Absence of standards</p> <p>No central portal or architecture</p> <p>No support for making data available</p> <p>Lack of meta standards</p> <p>No standard software for processing open data</p> <p>Fragmentation of software and applications</p> <p>Legacy systems that complicate the publicizing of data</p>

Janssen et al. (2012) also postulated that in between the benefits and barriers of open data are the myths associated to the concept. Being a myth a tradition or legend without base of fact or evidence supporting it, these authors concluded that an oversimplistic view still remained as per the interviews conducted. To be mentioned that the approach to myths is not of mere criticism and its importance is acknowledged as to representing a shared view of individuals and organizations (Janssen et al., 2012). Nevertheless, myths do not necessarily represent the truth as they are mostly fictional and unproven (Janssen et al., 2012). With roots in how individuals elaborate conceptual models and collectively put them to action, myths are believed to play an important role in policy-making, hence should not be ignored (Janssen et al., 2012). This being, it is of great importance to discuss the myths and to assess their relevance as an influencer of open data buy-in (Janssen et al., 2012). These authors identified five myths, hereby summarized.

The first myth, by no relevant order of importance, is that opening up data would directly result in a competitive advantage (Janssen et al., 2012). According to the authors that identified it, giving unlimited acces to data as little value if not provided the tools to process the data and to overcome potential barriers (Janssen et al., 2012). In addition, authors claim that publishing too much data can lead to difficulty finding right and meaningful information (Janssen et al., 2012). It can thus be concluded that creating value from open data is not necessarily equal to publicizing data; the linked technical infrastructures should de adapted so that the use of data can be accessible both to scientists and to the public (Janssen et al., 2012). Otherwise, the manipulation and analysis of open data are limited to an elit of highly knowledgeable users, which is contradictory to the concept definition earlier cited (Janssen et al., 2012).

Another myth pointed out by Janssen et al. (2012) is that existing policies on open data were uterly generic and fomented publicizing data as much as possible, without any criteria. Indeed as previously here described, several governments from indutrialised countries have been gathering efforts to make data a public asset as much as possible, in order to increase transparency and citizen participation (Conradie & Choenni, 2014; Huijboom & Broek, 2011). However, limitations may arise when pursuing these goals; to begin with, legislation on data privacy does not allow publicizing personal data (Janssen et al., 2012). This assumption is relevant for this research as most data produced in healthcare contextes is personal (Fernandez-Aleman, Senior, Lozoya, & Toval, 2013). Then, it can be said that personal data should be indeed out of the scope unrestricted data (Janssen et al., 2012). To be noted

though that this acknowledgment does not necessarily impose an impossibility of no-barrier data for healthcare. On the contrary, it theoretically emphasizes that open data is mistakenly taken as being the same as unrestricted data what indeed is opposite to the research; when establishing the current framework for sharing data in healthcare, it should be borne in mind that data that can be traced back to an individual should not be considered as such, so this insight from Janssen et al. (2012) is significantly relevant as to trim the edges of the research problem definition. Furthermore, it is duly noted that having generic policies do not suit reality and specific policies are needed (Janssen et al., 2012). Still, to be noted the existing paradox when it comes to data regulations; if on one hand several governments are adopting open data policies, on the other hand, law might prevent the publication of data (Janssen et al., 2012). Another particularly relevant outcome from Janssen et al. (2012) research is that the data subject to being shared may be processed in different ways, depending on its future usage. The particular example of criminal data is given as a means to exemplify that data should be processed in such a way that it may not be traced back to the individual (Janssen et al., 2012). Hence, it can be extrapolated the particular need for healthcare data to be faced the same way, in the sense that it should not be possible to link the data to the individual. This is indeed one of the key assumptions present when approaching the sharing of data in healthcare: it should not be traceable to the individual (Janssen et al., 2012).

Still on the list of myths about open data, the pre-established idea that it only requires publicizing it is stated (Janssen et al., 2012). This oversimplistic view arises from noticing that most policies rely on making data available, regardless of how prone it is to being used and interpreted (Janssen et al., 2012). Proposed solutions to overcome this include developing meta-data and standardizing the methods used to preprocess data (Janssen et al., 2012). This conclusion clearly overlaps with some of the barriers also listed by Janssen et al. (2012) with regards to making data accessible and user friendly. It is noticeable that several authors stress that open data should not be reductively considered as the publicizing of data itself but that it comprises all the resources ensembling the right conditions and environment to stimulate open data use (Hossain et al., 2016; Janssen et al., 2012).

A fourth myth to be considered is that everyone is capable of using data (Janssen et al., 2012). This is identified as an utopic idea in the sense that not every user is resourceful and skillful enough to make a valuable use of data (Janssen et al., 2012). As common sense as it may seem, it is worth highlighting that knowledge on data analytics techniques is not attributed to everyone (Hossain et al., 2016; Janssen et al., 2012). Here is understated the difference between making data available and making it usable by everyone (Janssen et al., 2012). This is a particularly important nuance in the context of the research; transposing to health data, the implied restriction of use of data to knowledgeable users can be a disadvantage as it can prevent unknowledgeable patients to make use of data. Thus, this is one of the assumptions considered when addressing the problem definition later on the empirical phase.

The last myth presented by Janssen et al. (2012) corresponds to the misunderstanding between the concepts of open data and open government. These authors emphasize that publicizing data is not necessarily synonymous of governmental transparency. Arguments as the one described above that open data is not readable by most of the public and also that the flow of communication should not be unidirectional - from government to citizens - and to obtain people's feedback would contribute to better accountability (Janssen et al., 2012). To retain from this point of view that there are more factors in the equation of open government than simply disclosing data (Janssen et al., 2012). This

insight is of significant value to the research as it establishes that to take the most out of data sharing, the flow should be bidirectional – from entities to citizens and vice-versa (Janssen et al., 2012).

From this investiture in the characterization of the state-of-the-art on open data it can summarily be extracted that its concept has evolved as time and research went by (Hossain et al., 2016; Janssen et al., 2012). It can be concluded that there are several benefits but that they are relatively generic which can be justified by the early stage of development of open data policies (Hossain et al., 2016) and not so much because open data lacks practical advantages and specific applicability (Janssen et al., 2012). Nevertheless, the promise and potential of open data should be framed with the barriers already identified (Hossain et al., 2016; Janssen et al., 2012). From here, the need for further research on the relationship between benefits and barriers is highlighted (Janssen et al., 2012).

Being still at an infant stage of development (Hossain et al., 2016), most authors emphasize the need for further research in this field (Hossain et al., 2016; Janssen et al., 2012; Meijer et al., 2014); not only to assess the current state but also to provide guidance for further research work (Hossain et al., 2016). To be highlighted that, as broad as the concept of open data can be to the specific goals of this research at a first glance, there are significant amount of insights to be taken from it. Most important for the transposal of this concept to healthcare is that it encompasses disclosing and sharing of information (Hossain et al., 2016; Janssen et al., 2012) and that it has the potential of increasing transparency and citizen empowerment (Hossain et al., 2016; Huijboom & Broek, 2011; Janssen et al., 2012). Ultimately, for the purpose of this research, open data was viewed and researched as a propaedeutics field contributing to formalize the discussion on health data sharing.

2.2. HEALTH DATA: FROM OPEN DATA TO HEALTH INFORMATION EXCHANGE

Having described and categorized open data, the proceedings of such analysis to the context of healthcare are addressed. Table 2.5 summarizes some of the papers selected at this stage.

Table 2.5 - Papers reviewed related to health data

Year	Author(s)	Publication	Title	Keywords
2008	Bloomrosen, M., Detmer, D.	Journal of the American Medical Informatics Association	Advancing the Framework: Use of Health Data—A Report of a Working Conference of the American Medical Informatics Association	N/A
2012	Bullinger A. C, Rass, M., Adamczyk, S., Moeslein, K., Sohn, S.	Health Policy	Open innovation in healthcare: Analysis of an open health platform	Open innovation, Public integration, Healthcare, Communication

2014	Wade, T. D,	Health Information Science and Systems	Traits and types of health data repositories	Registry, Observational research, Big data, Information commons, Data warehouse, Federated database
2014	Tavares, J., Oliveira, T.	WEBIST 2014 - Proceedings of the 10th International Conference on Web Information Systems and Technologies	Electronic Health Record Portal Adoption by Health Care Consumers Proposal of a New Adoption Model	eHealth, Technology Adoption, UTAUT2, Healthcare Consumers, eGovernment
2018	Tavares, J., Goulão, A., Oliveira, T.	Journal of Informatics for Health and Social Care	Electronic Health Record Portals adoption: Empirical model based on UTAUT2	eHealth, electronic health records, healthcare consumers, technology adoption, UTAUT2

Note. N/A = Not applicable

It was noted, first hand into this endeavor, that some studies in the field of healthcare adopt specific concepts to define the scientific movement of sharing information, such as *open innovation* (Bullinger, Rass, Adamczyk, Moeslein, & Sohn, 2012). Open innovation is then defined by authors as “the paradigm that assume that firms can and should use external ideas as well as internal ideas, and internal and external paths to market, as firms look to advance their technology” (Bullinger et al., 2012, p. 166). This is interesting to be pointed out in the sense that open source initiatives should not be narrowed down to the process of exchanging data *per se* but that they ought to be viewed as an innovation-creating phenomenon in which the public takes part (Bullinger et al., 2012). According to the same authors, the open innovation movement puts the public on central role as a source of acquisition of knowledge for the organizations, in what they call an outside-in flow of information (Bullinger et al., 2012). It is highly emphasized that *public*, in the healthcare context, should not be limited to patients but extended to caregivers and family who often play a key role in healthcare delivery (Bullinger et al., 2012). This perspective is much interesting as to provide an holistic approach that transcends the usual view of the recipient of healthcare as being the patient himself (Bullinger et al., 2012). It is also noted an adaptation underneath the concept of unlimited-access data when applied to healthcare context- from open data to open innovation (Bullinger et al., 2012). For the purposes of this research, the concepts are assumed to be similar and complementary.

Regarding the presentation of the current state, some authors claim that, to capitalize the potential of public integration, healthcare sector should shift from the traditional assumption that only healthcare professionals are able to develop and disseminate information to new assumptions according to which healthcare is a democratic process in which the public has the right to participate in (Bullinger et al., 2012). What is more, Bullinger et al. (2012) proposed a taxonomy to classify the degrees to which the public is integrated in the process of creating knowledge and experiential insights; revisiting a categorization dated 1969, three classes were distinguished: (1) *nonparticipation* i.e. letting to providers the onus of taking the course of action, (2) *tokenism* i.e. giving the public power to express themselves but still with no guarantee they will be the accountable ones and (3) *citizen power*. i.e. the public having the biggest weight on decision making (Bullinger et al., 2012). Same authors claim that, as of 2012, public involvement in healthcare research was at the level of *nonparticipation* or *tokenism*. However, subsequent studies that assessed this currently were not found, much less any research done to Portuguese population on this matter. Thus, there is a lack of an evolutionary view of this classification and a contextualization with the Portuguese society.

Leveraging on this discussion, it is important to specify what does health data comprise. The *American Medical Informatics Association* makes a distinction between primary use health data and secondary use health data (Bloomrosen & Detmer, 2008). Primary use data is defined as the “data collected about and used for the direct care of a patient” (p. 716) whereas secondary use data was defined as “non-direct care use of health data including, but not limited to, analysis, research, quality/safety measurement, public health, payment, provider certification or accreditation, and marketing and other business uses including strictly commercial activities” (Bloomrosen & Detmer, 2008; Safran et al., 2007, p. 716). Despite its relevance to the categorization of health data back in the day, Bloomrosen and Detmer (2008) concluded that this division into primary and secondary could be oversimplistic to categorize health data, considering the vast developments the sector has witnessed in the past years and the growth of health data in terms of volume and complexity. Thus, splitting health data according to this categorization could be useful for theoretical purposes but can be reductive to reflect the complexity of current health datasets (Bloomrosen & Detmer, 2008). Likewise, subsequent works debate on the use of health data but not limiting its categorization into primary or secondary (Bullinger et al., 2012). For instance, Bullinger et al. (2012) debate about what sharing information could do for medical research as a generic field whereas other authors specify the purposes that can be achieved by it, such as clinical or epidemiological research, to weave financial considerations or to measure the utilization of services (Parker, Weiner, & Reeves, 2016). So, in conclusion, authors differ in opinion with regards to the specific purposes met by health data usage but there is a common view on the potential it can have to improve experience, knowledge and effectiveness of healthcare systems (Bloomrosen & Detmer, 2008; Bullinger et al., 2012; Esmaeilzadeh & Sambasivan, 2016). Here, the theoretical substantiation of the relevance to discuss data sharing and usage in healthcare is understated.

Instead of establishing the boundaries of primary use data and secondary use data, the American Medical Informatics Association defended that policies should focus on how data is used, reused and protected (Bloomrosen & Detmer, 2008). To express this view, the concept of *data stewardship* was presented as a way of protecting the personal information of individuals and to improve health services sustainability (Bloomrosen & Detmer, 2008). By definition, data stewardship is “the responsibility and accountability associated with managing, collecting, viewing, storing, sharing, disclosing, or otherwise making use of personal health information. Principles of data stewardship should apply to all personnel, systems and processes engaging in health information storage and exchange within and

across organizations” (Bloomrosen & Detmer, 2008, p. 718). Thus, data stewardship is an interesting mental construction of what should be a guideline for the use and reuse of health data (Bloomrosen & Detmer, 2008). The paradigm of data stewardship then arises as a rationale for the appropriate and legitimate use of health data, before a context where growing volumes of data are collected and stored (Bloomrosen & Detmer, 2008). Seven principles are presented by the American Medical Informatics Association as to reiterate what data stewardship comprises (see Table 2.6) (Bloomrosen & Detmer, 2008).

Table 2.6 - Data Stewardship Principles (Bloomrosen & Detmer, 2008)

Data Stewardship Principles	
Accountability	Governance, oversight, and the application of relevant regulations to the appropriate extent and level
Transparency	Policies and procedures regarding data structure, processing, and delivery of data, and business processes and practices
Notice	To patients and other legitimate users
Technical	Data security, and quality, de-identification, and costs of re-identification
Consent	Patient consent of appropriate granularity
Uses	Permitted uses and disclosures including for data aggregation and analyses
Enforcement	Enforcement and remedies

It can be said that the notion of data stewardship is a first approach to the discussion of the legitimate uses of health data, bringing along with it the statement that a fair share of responsibility for the quality, security and confidentiality of data should be taken by all players of the supply chain of healthcare service (Bloomrosen & Detmer, 2008). To be noted that the application of stewardship is not limited to the healthcare field; examples can be also found in governmental organizations and technology industry (Bloomrosen & Detmer, 2008).

2.2.1. EHRs: key systems in health informatics

The background presented sets the tone for the discussion on the use and reuse of health data; as modern healthcare industry produces terabytes of medical data from mobile devices, wearables and sensors (Kostkova et al., 2016; Safran et al., 2007), from laboratorial records to pharmaceutical prescriptions, the Internet of Things generates an unprecedented level of personal data sharing nowadays (Kostkova et al., 2016; Safran et al., 2007). These large volumes of data are needed for researchers to extract meaningful information, especially when considering population studies and public health (Bloomrosen & Detmer, 2008). The epitome of how data-driven healthcare systems are currently is the adoption of electronic health records (EHRs) technologies by professionals and organizational providers (Parker et al., 2016). EHRs are a type of health data repository, mainly characterized for being wide in range (Wade, 2014). There are other types of health data repositories, briefly defined in Table 2.7, according to Wade (2014). All have in common containing personally

identified data but only releasing de-identified data (Wade, 2014). The difference between each of them lies in the level of integration, specific purpose, origin and quality of the data (Wade, 2014).

Table 2.7 - Types of Clinical Data Repositories (Wade, 2014)

Repository Type	Definition
Study	A database that collects observations for a specific clinical research study
EHR	A database of observations made as a result of direct healthcare
Registry	Observations collected and organized for the purpose of studying or guiding particular outcomes on a defined population. Associated studies are either multiple or long-term and evolving over time
Warehouse	A repository that adds levels of integration and quality to the primary (research or clinical) data of a single institution, to support flexible queries for multiple uses. Is broader in application than a registry
Collection	A library of heterogeneous data sets from more organizations than a warehouse or more sources than a registry. Organized to help users find a particular data set, but not to query for data combined across data sets
Federation	A repository distributed across multiple locations, where each location retains control over access to its own data and is responsible for making the data comparable with the data of other locations

For this research, efforts will be narrowed to EHRs, has having identifiable significance on cost reduction, on promoting an evidence-based medicine and on improving quality of care (Fernandez-Aleman et al., 2013). Due to the reported advantages (Fernandez-Aleman et al., 2013; Tavares & Oliveira, 2016; van der Linden, Kalra, Hasman, & Talmon, 2009) and also due to the importance it has assumed in governmental agenda the past few years (Fernandez-Aleman et al., 2013), it is relevant to address specifically this type of health repository.

So, what exactly are EHRs? Although there is no consensus on the precise definition of EHR, standard ISO/TS 18308 defends that its primary purpose is “to provide a documented record of care which supports present and future care by the same or other clinicians, being a means of communication among clinicians contributing to the patient’s care” (van der Linden et al., 2009, p. 143). A more recent definition published as standard ISO/TR 20514 insights on the purpose and scope of EHR as “a repository of information regarding the health status of a subject of care in computer processable form, stored and transmitted securely, and accessible by multiple authorized users. It has a standardized or commonly agreed logical information model which is independent of EHR systems. Its primary purpose is the support of continued, efficient and quality integrated healthcare and it contains information which is retrospective, concurrent and prospective” (van der Linden et al., 2009, p. 143). From both definitions it can be inferred that a patient’s EHR would be the total amount of personal health information stored in various systems (van der Linden et al., 2009). From here, it is noticeable an evolution with regards to the accessibility of EHRs; if the first standard reiterated that the recipients

of the information would be only clinicians, the second standard does not make such restriction, only claiming that access to data should be subject to authorization (van der Linden et al., 2009). This can be interpreted as an acknowledgement that data should become available to healthcare professionals and patients and not only to physicians. Complementarily, other authors, without directly defining the concept, refer the core functions a tool should have to be considered an EHR: electronic documentation of providers’ notes, results management, physician order entry, and decision support (Jha, Doolan, Grandt, Scott, & Bates, 2008). It can be retained that considering EHRs a computerized health record is an oversimplistic view and that it should be considered as a tool that creates the opportunity for aggregating clinical data and to support research and decision-making (Jha et al., 2008; Parker, Reeves, Weiner, & Adler-Milstein, 2017). Several authors have described the generic technical requirements EHRs should comply with, hereby in Table 2.8 summarized the ones related to security and privacy (van der Linden et al., 2009). Apart from security and privacy matters, EHR systems should also be satisfiable in terms of completeness, resilience and availability (Fernandez-Aleman et al., 2013). Despite the generic technical requirements of EHRs being consensual, challenge remains with regards to what, how and when these requirements ought to be implemented (van der Linden et al., 2009) so more research efforts should be made for that purpose.

Table 2.8 - EHRs Technical Requirements

EHR technical requirements	
Security	The most relevant requirements being: Authentication, Authorization, Data Integrity, Non-repudiation, Confidentiality and Consent
Semantic interoperability	Share data with other systems in compatible formats
Author responsibility	Track back each input to its contributor
Audit trail	Allow previous versions of the information to be restored and presenting information about access to and modifications of data
Version management and control	Support different versions and measures to distinguish modifications or updating
Patient access	Allow the patients to access all their EHR information
Archive	Move EHR information to storage with the possibility of restoring and provide the functionality to store it for at least the duration specified in legal requirements

Similarly to what presented for the broader movement of open data, it is also worth to discuss the benefits and barriers of information sharing in the context of healthcare in general and EHRs in particular. Data collected more than ten years ago in the U.S. already showed that physicians acknowledged the benefits of implementing ICTs, with the majority indicating that it could reduce errors, increase productivity, stimulate patient responsibility and reduce financial costs (Anderson, 2007). To what EHRs specifically are concerned, some authors claim that they have the potential of improving the quality of care and the promotion of evidence-based medicine (Fernandez-Aleman et al., 2013). Regarding the barriers, most papers reviewed highlighted that its high initial cost and uncertain payoff is one of the top obstacles (Anderson, 2007; Fernandez-Aleman et al., 2013). It can thus be concluded that financial incentives could overcome this obstacle and accelerate EHR adoption

(Anderson, 2007). Other barriers reside on the complexity of the systems, with physicians claiming that efforts need to be done to properly train the users (Anderson, 2007). What is more, due to the many vendors available in the market, system interoperability is a major barrier for EHR implementation (Anderson, 2007). Imposing the standardization of systems' specificities is a way of overcoming these technical obstacles (Anderson, 2007). To be retained, at this stage, that despite evolution in sophistication and functionalities, applications still present technical drawbacks and must be developed so they can be viewed as a facilitator for adoption instead of a barrier (Anderson, 2007)

In order to assess the state of information technology adoption by the healthcare industry, a study was conducted back in 2008 worth to be considered; although the potential of EHRs as tools for improving efficiency, quality and safety of health services was already acknowledged across the globe back then, the adoption rates in the U.S. were still significantly low (Costa et al., 2012; Jha et al., 2008). To get insights on how to improve adoption in the U.S., a comparison was made with six other industrialized countries - United Kingdom, Australia, New Zealand, Netherlands, Germany and Canada - finding simultaneously similarities and differences (Jha et al., 2008). Parallel analysis was done for ambulatory care and for hospital care with the most relevant findings being (1) most nations were far ahead the U.S. in adoption of EHRs in the ambulatory care, only Canada being comparably low and (2) hospitals across the seven nations had been slow to adopt EHRs (Jha et al., 2008). It is worth to be noted that North America was low ranked mainly due to different policies (Jha et al., 2008). Whereas in U.S. and Canada physicians lack governmental incentives, in Europe and Oceania factors like inexpensive software and governmental financial investment stimulated the use of EHR among professionals (Jha et al., 2008). As for the hospital care environment, Jha et al. (2008) proposed two explanations for the slow rate of adoption: the first one being the relative little attention payed to hospital EHRs and secondly the high cost of hospital EHR systems (Jha et al., 2008). From this point of view, it can then be implied that financial incentives and governmental encouragement play an important role in EHR adoption (Jha et al., 2008; Parker et al., 2016). It can be said that, similarly to what noticed for the generic open data movement previously presented, its successful application to health sector is influenced by political and financial factors (Jha et al., 2008; Parker et al., 2016). To be also highlighted that research contemplating Portugal's context was not found.

At that point lagging behind other developed nations, the scenario in the U.S. started to shift as a result of new federal investments and policies (Parker et al., 2016). In 2009, via the *Health Information Technology for Economic and Clinical Health* (HITECH) Act, the U.S. established the EHR Incentive Programs (Parker et al., 2016). With this programs, the United States aimed to encourage healthcare professionals to adopt and improve EHR technologies, not just to the recording of information but ultimately to improve patient care (Parker et al., 2016). These efforts - referred to as *Meaningful Use Act* - were the consubstantiation of governmental policies which resulted in the implementation of EHR technologies by 80% of all eligible hospitals and over half of physicians and other healthcare professionals, data as of May 2013 (Parker et al., 2016). More recent studies were looked for to demonstrate the current status of adoption of EHRs but searches did not retrieve relevant data. Nevertheless, the evolution from 2008 to 2013 is demonstrative that the increasing level of adhesion to the EHR technologies. Once again, most of the papers published concern the American reality only.

2.2.2. From local records to electronic exchange of data: the rise of health information exchange

Although the HITECH Act had significantly impact on health information technologies in the U.S, it is relevant to mention that the potential of EHRs in terms of quality and efficiency started to meet reputation long before it, back in the 1980s and 1990s, more precisely (Kuperman, 2011). However, even experiencing success ever since, it became clear from early on that siloed EHRs would fail to meet the purpose of patient care coordination as they were first implemented with only local usage in mind (Campion, Edwards, Johnson, & Kaushal, 2013; Kuperman, 2011; van der Linden et al., 2009). Here lies yet another important feature of the Meaningful Use program; at a later stage, one of the requirements of the program would be for clinical information to be securely exchanged across institutions and providers (Parker et al., 2016). Such requirement, along with the outburst of EHRs led to the development of *Health Information Exchange* (HIE) organizations, rising out from the need of electronically sharing the information recorded in EHRs (Parker et al., 2016). HITECH Act defines HIE organizations as the responsible entities for overseeing and governing the exchange of health-related information among organizations according to nationally recognized standards (Parker et al., 2016). This being, it can be noticed that when it first came out, HIE were entities aimed at fostering the creation of mechanisms to manage data collection and usage, capable of being shared across different EHRs technologies (Parker et al., 2016).

But what were the drivers for HIE emergence? This terminology and concept came to life in the American context, were patients typically receive care from unrelated providers that maintain separate records (Grossman, Kushner, & November, 2008). Thus, to fully leverage on health information technologies, stakeholders not only had to implement EHRs systems but also to share the data electronically to allow access across all sites and levels of care (Grossman et al., 2008). It can be implied that the embedded trend in this axiom meets the impellent behind the open data movement previously discussed, which is that data is only valuable when shared (Hossain et al., 2016; Molloy, 2011; Murray-Rust, 2008). It is thus noticeable the resemblance of drivers behind HIE and the broader open data movement, concluding its interrelatedness (Grossman et al., 2008; Molloy, 2011; Murray-Rust, 2008).

Healthcare sector was then before a context in which HIE was introduced to potentiate the development of a strategy towards an health information network at national level (Grossman et al., 2008). Worth to clarify at this point that some authors reinforce that transferring and exchanging information should not be taken as the same (Lee & Garvin, 2003); this view, dated 2003, was already a statement that healthcare professionals should shift from traditional practices of information transfer towards a bidirectional flow of communication - information exchange (Lee & Garvin, 2003). It is interesting to note that this view preceded the American HIE strategy understated in the Meaningful Use Act but it already provided recommendation that a change in the paradigm of health information communication should take place, if aiming to strengthen patient participation (Lee & Garvin, 2003). More than a decade later it is concluded that this chain of though not only persists but has actually been reinforced (Esmailzadeh & Sambasivan, 2016; Parker et al., 2016).

There are many variables influencing HIE initiatives such as user participation, technology, strategy, among others (Esmailzadeh & Sambasivan, 2016). To explain the adoption process of HIE, Esmailzadeh and Sambasivan (2016) reviewed the literature and proposed a new evolutionary-based

classification with four main phases of HIE assimilation in healthcare context: *initiation*, *adoption decision*, *implementation process* and *institutionalization* (see Table 2.9).

The first phase, *initiation*, comprises the awareness of HIE services by organizations and individual users (Esmaeilzadeh & Sambasivan, 2016). Considered to be the building blocks for assimilation, stakeholder buy-in can only be achieved by presenting the potential benefits and gains of HIE initiatives, hence the importance of this step (Esmaeilzadeh & Sambasivan, 2016).

At the end of this phase, organizations can either stop the adoption process or move on to the second phase, *adoption decision* (Esmaeilzadeh & Sambasivan, 2016). At the beginning of this second stage, financial factors are the ones playing the key role; funding is decisive when motivating organizations as a resourceful setting would be keener to embrace the integration of HIE services (Esmaeilzadeh & Sambasivan, 2016). Summing up, if the financial, organizational and legal issues are solved, organizations will move forward; if not, organizations may be impelled to remain at this stage due to financial constraints and lack of organizational preparation (Esmaeilzadeh & Sambasivan, 2016).

The third phase - *implementation* - occurs when decision is made on the adoption of HIE, having it two dimensions: setup and execution (Esmaeilzadeh & Sambasivan, 2016). During setup part, a plan for the implementation of HIE systems is developed, according to the scope and objectives to be met (Esmaeilzadeh & Sambasivan, 2016). Possible drawbacks, concerns and changes must be considered in anticipation so that the implementation occurs smoothly (Esmaeilzadeh & Sambasivan, 2016). During execution, the previously developed plan is executed, relying on the implementation of HIE systems (Esmaeilzadeh & Sambasivan, 2016). At the end of this process, HIE systems are available but the dynamics of implementation has not ended; resource reallocation may occur based on the assessment of needs that should take place ongoing (Esmaeilzadeh & Sambasivan, 2016). It can then be said that the assimilation of HIE systems is an iterative process that relies on a multi-dimensional environment (Esmaeilzadeh & Sambasivan, 2016). Similarly to the other phases, implementation may be also subject to being terminated if setup or execution fail to go according to the designed plan (Esmaeilzadeh & Sambasivan, 2016).

Institutionalization is the last phase identified and it corresponds to the integration of HIE systems into the organizational infrastructure (Esmaeilzadeh & Sambasivan, 2016). Authors emphasize that HIE may be used only partially, as healthcare professionals may be compelled to exchange information only with related institutions and leave behind unaffiliated ones (Esmaeilzadeh & Sambasivan, 2016). Under this partial use, the full potential of HIE is not achieved and healthcare professionals may be impelled to be selective when sharing clinical information (Esmaeilzadeh & Sambasivan, 2016). These different degrees to which healthcare organizations engage in HIE are strongly influenced by privacy, security, technical and competition concerns (Esmaeilzadeh & Sambasivan, 2016). Hence, it is realizable that, besides the financial factors pointed before, other ones influence the implementation of HIE technologies and only by overcoming them HIE, full potential can be met in terms of usefulness and effectiveness (Esmaeilzadeh & Sambasivan, 2016).

To sum up, this work by Esmaeilzadeh & Sambasivan (2016) is relevant both because it proposes a pattern for HIE assimilation in detail but also because it specifies the policies required to facilitate initiatives. What is more, the work from these authors represents a breakthrough to what policies related to HIE adoption are concerned; from the focus on technical barriers, attention is given to the

non-technical barriers such as lack of cooperation between providers (Esmaeilzadeh & Sambasivan, 2016).

Table 2.9 - Phases of HIE Assimilation (Esmaeilzadeh & Sambasivan, 2016)

Phase	Dimensions
Initiation	Awareness and raise of interest
Adoption decision	Share data with other systems in compatible formats
Implementation	Track back each input to its contributor
Institutionalization	Allow previous versions of the information to be restored and presenting information about access to and modifications of data

Keeping the American context as benchmark, it is worth to point out that U.S. government, via its health information technology initiatives, divides health information exchange into three types. *Direct exchange*, is defined as the way information is electronically exchanged between healthcare professionals in an encrypted and secure form (The Office of the National Coordinator for Health Information Technology, 2018). Commonly compared to sending a secure email, it has the potential of preventing duplication of tests and medication errors, thus supporting a coordinated care approach. (The Office of the National Coordinator for Health Information Technology, 2018). Another type, *query-based exchange*, is described as the ability to search and request information on a patient, often in the context of unplanned care (The Office of the National Coordinator for Health Information Technology, 2018). At last, *consumer-mediated exchange* is the means to provide patients access to their own health information, allowing them to aggregate and control the use of their data among providers (The Office of the National Coordinator for Health Information Technology, 2018). Providing patients an active participation in their health information management has as potential outcomes (1) to identify incorrect or missing information, (2) to track and monitor health status and (3) to provide healthcare professionals their health information (The Office of the National Coordinator for Health Information Technology, 2018). Although this categorization of health information was setup with the American healthcare system as background, it will be considered relevant and replicable to the Portuguese health system, thus having it into account when defining the research problem.

It is important to notice that the consumer-mediated exchange is not just a type of HIE but it also represents a shift in the nature of the doctor-patient relationship (Edwards, Davies, & Edwards, 2009). The relationship between health experts and the public has been defined by the dominance of the first over the second, leaving the patient with low level of control and power over their health (Edwards et al., 2009). Putting the patient at central stage when managing their health information (The Office of the National Coordinator for Health Information Technology, 2018) is a step forward to the emergence of a reflexive consumer who is able to better challenge and evaluate healthcare service delivery (Edwards et al., 2009).

2.2.3. Putting the patients in the equation: EHRs leading the way to EHR Portals

It is with the this scenario of patient-centered healthcare delivery as background (Tavares et al., 2018) that again the research field is refined; as healthcare consumers are becoming more active and informed (Tavares et al., 2018), what is their role in managing their health data stored in EHRs? Online

healthcare applications started to appear to allow patients to interact and communicate with their healthcare providers - EHR portals (Cruz-Cunha et al., 2016). By definition, EHR portals combine a system for accessing patients' EHRs and the possibility for patients to be active players in the management of their health data (Cruz-Cunha et al., 2016). As intricate as the relationships and differences between these concepts can be, their definitions are displayed in Table 2.10 (Cruz-Cunha et al., 2016). Among the definitions presented, it is important to notice the difference between EHRs – earlier in this chapter addressed - and EHR portals. If the first refers to a repository of health data, the second can be considered as the interface for supporting patients in managing their own activities (Cruz-Cunha et al., 2016; Tavares & Oliveira, 2017). To note that, in the literature, EHR portals are also referred to as EHR patient portals, thus for this research being considered as equivalent concepts (Tavares & Oliveira, 2017).

Table 2.10 - Overview of the definitions and differences between main concepts related to EHRs (Cruz-Cunha et al., 2016)

Concept	Definition
eHealth	The transfer of medical topics and health care by electronic means
EHR System	IT platform for realizing the mechanisms of creating, using, storing, and retrieving an EHR
Electronic Health Record (EHR)	Repository of patient data in digital form, stored and exchanged securely
Patient Portal	IT Platforms that allow patients to interact and communicate with their healthcare providers
EHR Portal	Web based application that combines an EHR System with a Patient Portal

Proceeding to delineate the research question, efforts were centralized on the EHR portals problematic. This is justified by the fact that there is extensive and in-depth literature on the adoption of EHRs by healthcare providers but few research focusing on the patients (Angst & Agarwal, 2009). What is more, EHR portals can greatly help to achieve benefits for both patients and healthcare providers (Tavares & Oliveira, 2014). From the patients point of view, EHR portals have the potential of giving the access and visibility over their own health records (Angst & Agarwal, 2009). From the providers point view, EHR portals can improve efficiency and reduce medical errors and administrative costs (Angst & Agarwal, 2009; Tavares & Oliveira, 2014).

However, there is a major downside related to EHR portals which is the patients' concern for the privacy of the data stored (Angst & Agarwal, 2009). In the literature this *concern for information privacy* (CFIP) is addressed as having become one of the issues in the top of the agenda of medical informatics research, as patients are manifestly disturbed about the information collection and usage practices (Angst & Agarwal, 2009). To be emphasized that data privacy and security was an issue identified for all fields of research explored; from open data to health data, passing by EHRs, information privacy and security were addressed in most papers analyzed, as a concern for users and policy-makers (Angst & Agarwal, 2009; Kobayashi, Kane, & Paton, 2018; Meijer et al., 2014; Meingast, Roosta, & Sastry, 2006; van der Linden et al., 2009).

It became apparent at this stage of the research the positive impact EHR portals can have in healthcare delivery (Angst & Agarwal, 2009) and thus, the importance of studying and understanding its adoption (Tavares et al., 2018). Although EHR portals offer the potential of transforming the healthcare sector, information technologies sometimes fail to have into account the perspective from all the actors (Angst & Agarwal, 2009). Therefore, having the perspective from key stakeholders was identified as the foundation to address the research problem empirically.

To summarize, EHR portals are described in the literature as desirable applications, capable of radically changing healthcare systems, both from a provider and patient standpoint (Angst & Agarwal, 2009; Tavares & Oliveira, 2014). Nevertheless, many information technologies fail to succeed due to not taking into account the perspectives from the main players involved (Angst & Agarwal, 2009). In the particular case of EHR portals, no robust literature was found that would address the problem based on this rationale, hence the theoretical justification of this research.

Summing up this contextualization with healthcare, it can be said that the concept of open data was adapted to health information exchange (Parker et al., 2016; Shapiro et al., 2006); as health data contains sensitive and private information, the level of openness of health information needs to be restricted (Kobayashi et al., 2018), thus the initial concept of open data being reframed. Health information exchange initiatives arouse from the need of sharing the information (Parker et al., 2017, 2016), as a means to a more democratic healthcare service delivery (Bullinger et al., 2012). From HIE, the EHRs were defined and brought to the agenda as the technologies allowing the electronic exchange of data (Parker et al., 2017, 2016; van der Linden et al., 2009; Wade, 2014). Several concepts are related to EHR technologies - eHealth, EHR Systems Electronic Health Records, Patient Portal and EHR Portals (see Table 2.10). For the research, efforts were channeled to the studying of EHR portals, as having research focusing on patients was identified as a gap by some authors (Angst & Agarwal, 2009). What is more, EHR portals are worth being addressed due to the potential benefits for the stakeholders of healthcare systems (Angst & Agarwal, 2009; Tavares & Oliveira, 2014, 2016, 2017).

2.3. THE PORTUGUESE HEALTH SYSTEM: CHARACTERIZATION AND THE POTENTIAL ROLE OF EHR PORTALS

Having defined the concepts and identified the gaps that sustain the research, it is important to frame it with the context in which it will be addressed: Portugal. At this stage, the goal was to characterize the Portuguese health system and to identify the advantages EHR portals could have on it. Table 2.11 summarizes the most relevant literature relied on to characterize the Portuguese health system.

Table 2.11 - Papers Reviewed Related to Portuguese health system

Year	Author(s)	Publication	Title	Keywords
2011	Barros, P. P., Machado, S. R., Simões, J. A.	European Observatory on Health Systems and Policies	Portugal. Health system review.	Delivery of health care, Evaluation studies, Health care reform, Health system

				plans, Portugal
2017	Simões, J. A, Augusto, G. F., Fronteira, I., Quevedo, C. H.	European Observatory on Health Systems and Policies	Portugal Health system review	Delivery of health care, Evaluation studies, Health care reform, Health system plans, Portugal

In terms of organization and governance, the Portuguese health system is characterized by three co-existing and overlapping systems: (1) the National Health Service (NHS), (2) insurance-based schemes for certain professions or companies (health subsystems) and (3) private voluntary health insurances (De Almeida et al., 2017). To understand the complexity of the system, it is worth to characterize each one in detail.

Starting by the public side of the system, the current NHS was established in 1979, arising from the principle of every citizen's right to health and embodied in the new democratic constitution from 1976 (Barros et al., 2011). Until then operated by the social welfare system and religious charities, district and central hospitals as well as other health facilities were brought together under a universal, comprehensive and free-of-charge National Health Service (Barros et al., 2011). Several changes were introduced to the NHS since its creation, namely the introduction of user fees (Barros et al., 2011). However, exemptions are contemplated, to assure all citizens would have access to health care regardless of their economic and social background (Barros et al., 2011). Following the creation of the NHS, the Portuguese health policy went through several periods, culminating, in the beginning of the twenty-first century, on a mixed system, based on the interaction between the public and the private sectors, integrating primary, secondary and long-term care (Barros et al., 2011; De Almeida et al., 2017).

By 2011, in the middle of the economic crisis, the *Economic and Financial Adjustment Program* brought a number of cost-containment measures, including to the health sector (Barros et al., 2011). Being the NHS predominantly financed through general taxation, the aim was to cut public expenditure and increase the system's efficiency (Barros et al., 2011; De Almeida et al., 2017). Overall, most of the adjustment in spending in the health sector resulted from price effects, few from quantity cuts, and only a small part was due to shift of financial responsibility from the government to citizens (De Almeida et al., 2017). That was achieved through a reduction in the level of salaries paid to health workers, cuts in public pharmaceutical expenditure, and price review regarding private institutions that have contracted with the NHS (De Almeida et al., 2017).

The development and overseeing of health policies is the responsibility of the Ministry of Health, on behalf of the central government (Barros et al., 2011; De Almeida et al., 2017). Its core functions are the regulation, planning and management of the NHS but also the regulation, auditing and inspection of private health care providers, whether they are part of the NHS or not (Barros et al., 2011; De Almeida et al., 2017). The Ministry of Health comprises several institutions: some under direct

government administration, some integrated under indirect government administration, others having public enterprise status, a health regulatory agency and a consultative body (De Almeida et al., 2017). To the context of this research, the most relevant institution under the hierarchy of the Ministry of Health is the *Shared Services of the Ministry of Health*, EPE (SPMS from the Portuguese *Serviços Partilhados do Ministério da Saúde*). SPMS is, in legal terms, a public enterprise entity, which provides specific shared health-related services in matters of procurement and logistics, financial management, human resources, information and communications systems, and other supplementary activities to organizations that are part of the NHS (De Almeida et al., 2017). Health information systems are thus at the center of SPMS' activity, being this entity responsible for several initiatives, projects and products (SPMS, 2018). One of them is the NHS' EHR portal - *Portal do Utente* (SPMS, 2018; Tavares & Oliveira, 2014). The portal can be considered part of the broad governmental strategy that aims to facilitate services and communications between public services and the citizens and registered half a million users as of 2012 (Tavares & Oliveira, 2014).

In terms of strategy, the main guidelines and objectives for the NHS, for a specific period of time, are established in the *National Health Plan* (Barros et al., 2011; De Almeida et al., 2017). This Plan involves many players, including policy-makers, academics, health professionals and members from the civil society and has lately focused on patient empowerment and, within it, on patient information (Barros et al., 2011; De Almeida et al., 2017). These authors lay emphasis on the fact that well-informed patients make better use of healthcare services, thus saving time and resources for themselves and for the system (Barros et al., 2011). Mediating the relationship of information-keen patients and healthcare systems are eHealth technologies (Tavares & Oliveira, 2014). Thus, the importance of eHealth technologies in general and EHR portals in particular not only is presented in foreign literature but is also subject of significance in studies having Portugal as scenario (Tavares & Oliveira, 2014).

But does the Portuguese population use eHealth technologies? Data as of 2007 showed that approximately 30% of the population in Portugal already used the internet for health purposes, which was considerably less than Northern European countries like Denmark and Norway, where more than 50% of the population used internet for health purposes (Bouzas-Lorenzo & Lago, 2013). More recent figures on the usage of eHealth technologies were not found in the literature. Nevertheless, from the patients' side, it is known that most Portuguese population is covered by internet which, at least theoretically, allows patients to access health information sources (De Almeida et al., 2017). From the providers' side, only the NHS was found to be described in the literature in the scope of the patient empowerment strategy; having developed websites for all the constituent institutions, the Ministry of Health aimed to publicize information on available services and reports on quality of care (De Almeida et al., 2017).

Proceeding in the characterization of the Portuguese health system, there are the health subsystems (Barros et al., 2011; De Almeida et al., 2017). These can be described as health insurance schemes for which membership is based on professional or occupational category and the access is generally limited to members of a specific profession and their families (Barros et al., 2011; De Almeida et al., 2017). In addition to the universal coverage by the NHS, 16% of the population is covered by a subsystem (De Almeida et al., 2017). These subsystems can be public or private, according to the employer's nature, are normally financed through employer and employee contributions (De Almeida et al., 2017).

At last, regarding the private voluntary health insurances, they were introduced in 1978 and Initially, only group policies were offered (Barros et al., 2011; De Almeida et al., 2017). Individual policies became available later in 1982 (Barros et al., 2011; De Almeida et al., 2017). Approximately 10% of the population was covered by private health insurances in 2006 (Barros et al., 2011), thus less than the population covered by health subsystems. Nevertheless, the number of people insured raised significantly since early 90's (De Almeida et al., 2017).

There is the possibility of double or even triple coverage, that is, patients who benefit from the NHS, a health subsystem from their job, and a private health insurance (Barros et al., 2011; De Almeida et al., 2017). This can be attributed to the fact that the access to either private health insurance or health subsystems coverage is associated with better self-reported health status and with higher usage of services (Barros et al., 2011). Nevertheless, the health care providers and subsystems should be considered as having a supplementary role to the NHS rather than providing an alternative to it or competing with it (De Almeida et al., 2017).

Resuming, the health care delivery system in Portugal consists of a network of public and private health care providers, each of them connected to the Ministry of Health, acting as the coordinator of all health care provision and as the entity financing the public health care delivery (De Almeida et al., 2017). This gives patients the possibility to have multi-coverage of health systems and thus having the freedom to choose among many providers (Barros et al., 2011; De Almeida et al., 2017). A breakthrough of the e-government strategy in healthcare was the creation of NHS' EHR Portal; the patient-directed pillar of EHR has the potential, on the one hand, to improve health systems efficiency (Costa et al., 2012) and, on the other hand, to give patients an active role in the information cycle, giving them access to information that is key to their decision-making processes (Barros et al., 2011; De Almeida et al., 2017; Tavares & Oliveira, 2014).

To summarize the main insights of this literature review, starting from the broader concept of open data, the research was narrowed down to health information exchange. The latter was considered, in this research, to be the transposal of the open data movement to the context of health, in the sense that it comprises exchanging data in a way that allows its reuse (Hossain et al., 2016; Janssen et al., 2012; Jha et al., 2008; Lee & Garvin, 2003). ICTs play a key role on health information exchange and, among them, EHRs in particular make the electronic storing, transmission and access of health data a possibility (van der Linden et al., 2009; Wade, 2014). There are several components of EHR technologies (Cruz-Cunha et al., 2016), among which the EHR portals are the patient-directed applications that enable the interaction and communication with healthcare providers (Cruz-Cunha et al., 2016; Tavares & Oliveira, 2014). Considering the many benefits EHR portals present to healthcare systems (Angst & Agarwal, 2009; Tavares & Oliveira, 2014), they were established as the main focus of the research. What is more, the need for research that would have into consideration different stakeholders (Angst & Agarwal, 2009) was the driver for studying EHR portals from the perspective of providers and patients.

3. METHODOLOGY

Having characterized the state-of-the-art in the research areas relevant to the problem, in this chapter the methodology used to achieve each one of the proposed objectives is addressed. For that, it is relevant to revisit the research question and to perform a breakdown of its constituent parts.

Being the research question *What is the view from providers and patients on EHR portals in Portugal?*, it was understandably needed to design a study that would embed collecting the perspective from the two groups of stakeholders in question: healthcare providers and patients. This led to the organization of the research and objectives in two building blocks: a *provider-centered* approach and a *patient-centered* approach.

To be highlighted that the terminology *patient* is in this research used as a generic terminology to express the users of healthcare services, as it was noticed to be used in English-written literature issued in Portugal about health systems (Barros et al., 2011; De Almeida et al., 2017). Nevertheless, for the purposes of this research, the terms *citizens* or *users* should be considered the same as, ultimately, all citizens in Portugal have access to at least one healthcare provider - NHS (Barros et al., 2011).

Thus, the methodological approach was split having in mind this dichotomy of providers and patients and the objectives were set according to this approach as well. For the objectives, four in total, it was established how each would be achieved, what type of data needed to be collected and which study it led to. Table 3.1 compiles this approach, hereby summarized but subject to further drilling-down in next subchapters.

On the *provider-centered* approach two objectives were established: (1) To characterize the point of view of healthcare providers on EHR portals and (2) To identify the functionalities of the EHR portals available in Portugal.

On the *patient-centered* approach two objectives were set, continuing to number them according to Table 3.1: (3) to identify the EHR portals patients are using and the functionalities they find more important and (4) to verify the determinants of adoption of EHR portals. To be highlighted that to achieve objectives (3) and (4) the same data collection method was used.

Table 3.1 - Overview of objectives, data collection methods and studies

Approach	Objective	How was achieved	Type of data collected	Study
Provider-Centered	(1) To characterize the point of view of healthcare providers on EHR portals	Gathering information from providers on EHR portals current state and potential developments	Qualitative: standardized open-ended interviews	Study 1 Description of providers' view on EHR portals
	(2) To identify the functionalities of the EHR portals	Comparing the functionalities offered with the ones described in literature	Qualitative: Observational analysis of each portal's functionalities	Study 2 Comparative analysis of EHR portals' functionalities

Approach	Objective	How was achieved	Type of data collected	Study
	available in Portugal			
Patient-Centered	(3) To identify the EHR portals patients are using and the functionalities they find more important	Understanding which portals patients are using and the functionalities they look for	Quantitative: Questionnaire to patients	Study 3 Characterization of patient adoption of EHR Portals
	(4) To verify the determinants of adoption of EHR portals	Identifying the factors influencing adoption		

This methodological approach can be characterized as a mixed methods research because more than one type of data collection procedure was followed (Tashakkori & Creswell, 2007). Also, both qualitative and quantitative data collection methodologies were chosen, in order to get a multifaceted approach; with qualitative methods it is possible to address issues in depth and detail and with quantitative methods it is possible to achieve measurement standardization and the possibility to aggregate data (Patton, 2002). Because qualitative and quantitative methods have different strengths and weaknesses, the aim was to exploit the best of each in this multi-method approach (Patton, 2002). Further subject to detail in next subchapters, the methodology used for each study was: study 1- qualitative interviewing, study 2- design science research and study 3- natural science research (see Figure 3.1).

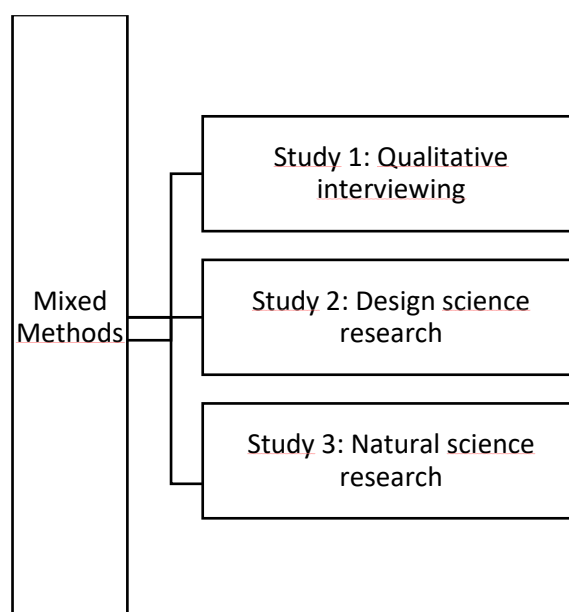


Figure 3.1 - Research methodology used for each study

For organization purposes, the methodology for each study is hereby presented separately and same organization will be adopted for next chapter of results and discussion.

3.1. PROVIDER-CENTERED APPROACH

On the provider-centered approach, the proposal was to describe healthcare providers' view on EHR portals current state and upcoming developments, which led to *Study 1: Description of providers' view on EHR portals* (see Table 3.1). Still in the provider-centered approach, there was the intention to identify the functionalities of EHR portals, which originated *Study 2: Comparative analysis of EHR portals functionalities* (see Table 3.1). Next, the methodologies used for studies 1 and 2 are detailed.

3.1.1. Study 1: Description of providers' view on EHR portals

With this first study, the aim was to achieve objective (1) to characterize the point of view of healthcare providers on EHR portals. It was then established that gathering information from providers on EHR portals was the means to achieve it. The data collection method chosen to design this study was the qualitative design of interviews (Patton, 2002). According to Patton (2002), interviewing serves the purpose of entering into other's perspective, which was ultimately the goal: to collect the perspective from healthcare providers on EHR Portals. What is more, interviewing is taken as an useful approach to have in mixed-methods research as to combine with other methods, approach adopted in this research (Mosley, 2012).

Decided that was to rely on qualitative interviewing for this study, the type of interview pertinent to adopt was then chosen. From the three alternatives suggested by Patton (2002) - informal conversational interview, interview guide and standardized-open ended interview, the latter was the approach chosen as better fitting the needs. Because it permits to design carefully and fully each question beforehand, it was selected as the most suitable approach as it makes easier the presentation of the findings and it facilitates the comparison of responses (Patton, 2002). The structure of the open-ended interview designed beforehand is presented as Appendix A in Portuguese, as it was the language in which the interviews would take place.

Having formulated the objective and the design to use in this study, it is now detailed the sampling strategy. The methodology adopted to select the providers to interview was the purposeful sampling, proposed by Patton (2002). With this strategy, the intent was to select participants that would allow to get relevant information from, to meet the purpose of the study (Patton, 2002). These so-called information-rich cases, were selected to allow in-depth understanding of the problem (Patton, 2002). Understandably, the first criteria of this non-random selection of participants (Patton, 2002) was that each provider should have its own EHR portal and have subscription free of charge. Fulfilling this criteria and considering the multiplicity of systems that compose the Portuguese health system (De Almeida et al., 2017), the purposeful sampling was set as having at least one representative of each. The information-rich cases were established to be (1) NHS as the public provider, (2) private providers representing the private voluntary health insurances and (3) representatives of an health subsystem as the insurance-based schemes that cover certain professions (De Almeida et al., 2017).

As representatives of the private providers, the selection was directed to elements of relevant weight and name within the Portuguese health system, and that would locate in greater Lisbon, to leave the possibility of an in-person interview opened. Under these criteria, the following providers were

selected: (1) Group José de Mello Saúde, owner of Hospitals and Clinics CUF® (from now on referred to as CUF®, for shorten) (2) Group Luz Saúde® (from now on, Luz®) and (3) Group Lusíadas Saúde® (from now on, Lusíadas®).

At last, as representative of the health subsystems, it was selected one of the private schemes available for professionals of the banking industry, *Serviços de Assistência Médico-Social do Sindicato dos Bancários do Sul e Ilhas* (from now on SAMS SBSI®). The reason for selecting this subsystem was that the author of the study is a beneficiary of it, and the entitlement to access and navigate its portal was then assured. Thus, the author was limited when choosing the representatives of this category as, for not being a beneficiary, access to other provider’s portals were considered as unlikely to be granted.

In Table 3.2 are summarized the providers contacted for interview. The contacts were established during February 2018, using email as communication vehicle for all providers except SAMS SBSI®. For this provider, the contact was established via the contact form available on the website, as information about the institutional email was not found. In the messages sent to the provider’s institutional emails, the general context and aim for the interviews was explained, as well as the availability to conduct them preferably in person but also in writing, by providing the questions to be posed.

Table 3.2 - Summary of Providers Contacted

Category	Provider	Communication channel
Public	NHS	Email
	CUF®	Email
Private	Luz®	Email
	Lusíadas®	Email
Subsystem	SAMS SBSI®	Contact form

Resuming the first study, it was intended to achieve objective (1) of this research via a qualitative design of interviews to healthcare providers to understand their view on EHR portals.

This being, these interviews were established as a preliminary research, as were planned to occur before the collection of data from studies 2 and 3. This is an approach described in the literature, according to which interviewing is a valuable source of information in preliminary research, even if the research project relies on other sources of data (Mosley, 2012).

3.1.2. Study 2: Comparative analysis of EHR portals’ functionalities

With the second study, the intention was to establish the path to achieve objective (2) to identify the functionalities of EHR portals available in Portugal. It was determined to be accomplished by comparing the functionalities offered by each portal with the ones described in literature.

After extensive research of the literature, the methodology adopted for the study was design science research methodology (DSRM). This methodology has gained significantly importance in information

technology research and it attempts to create constructs that serve human purposes (March & Smith, 1995; Peffers, Tuunanen, Rothenberger, & Chatterjee, 2007).

This methodology fitted the needs of this study because it is characterized by *building* and *evaluating* constructs (March & Smith, 1995). According to these authors, the building phase corresponds to the construction of artifacts that serve specific purposes and evaluation phase comprises the assessment of that artifact's performance. The implementation of DSRM in this study girds up to the second activity only - evaluation - as the intention was to evaluate artifacts already built - the EHR portals. The last activity, then, suited the purpose of this study, as it aims to provide answers to the question of how well does the artifact work (March & Smith, 1995). In this context, the intention was to give responses to the question of how well do EHR portals perform in terms of functionalities offered.

A requirement to evaluate artifacts according to DSRM is to develop metrics according to which the artifacts are measured (March & Smith, 1995). In this study, the metrics to evaluate the portals' performance were the framework proposed by Pagliari, Detmer and Singleton (2007). These authors identified the potential functions of EHR portals, therefore, their work was used as a benchmark for which are the functionalities to be presented by these platforms.

Table 3.3 presents the functionalities assessed but it must be noted that the classification of *functionalities* and *sub-functionalities* was done for organization purposes and for schematic result presentation. Such classification was not done by the authors, whom describe the features generically as *functions* and subsequently enumerate examples of such features (Pagliari, Detmer, & Singleton, 2007).

Table 3.3 - Potential functionalities of EHR Portals (Pagliari et al., 2007)

Functionality	Sub-Functionality
Access to provider's EHR	Clinical history
	Test results
	Medication
Personal health organizer	Clinical agenda
	Assistant Doctor
Self-management support	Care Plans
	Graphing of symptoms
	Customized instructive or motivational feedback
Communication	Booking appointments
	Reordering prescriptions
	Seek advice (example patient-doctor email)
Information repository	About illnesses
	About treatments
	About self-care
Sources of support	Patients organizations/associations
	Virtual peer networks

Capture of symptoms or health behavior data	Via self-report
	Monitoring through electronic devices

The type of data collected in this analysis was established to be qualitative because the aim was to determine if the portals present or not each functionality, and not to assess its usability or the degree of development.

Besides comparing each portal's functionalities with the ones described in literature, the goal was also to make a comparative analysis between them. The portals selected for evaluation were the ones from the providers contacted in study 1 (see Table 3.2). The principle of purposeful sampling was again taken into account for selecting the portals (Patton, 2002), with the reinforcement that it was intended to evaluate the portals of which it was expected to interview the providers. Table 3.4 makes the correspondence of the providers approached in the scope of study 1 to their correspondent portals and each portal website.

Table 3.4 - Correspondence of providers approached in Study 1 and EHR portals analyzed in Study 2

Category	Provider	Portal name	Portal website
Public	NHS	"Portal do utente"	https://servicos.min-saude.pt/utente_auth/utente/
	CUF®	"MyCUF"	https://www.saudecuf.pt/mycuf/
Private	Luz®	"Portal do Cliente"	https://portalcliente.luzsaude.pt/pt/
	Lusíadas®	"O Meu Portal"	https://omeuportal.lusiadas.pt/
Subsystem	SAMS SBSI®	"MySAMS"	https://marcacoes.sams.pt/

Resuming the second study performed, it was intended to achieve objective (2) of this research work by applying one of the activities of DSRM - evaluation. This approach was meant to measure the performance of the selected portals - the artifacts - by comparing the functionalities they offer with the ones identified in literature.

3.2. PATIENT-CENTERED APPROACH

On the patient-centered approach, the aim was to identify the portals that patients in Portugal are using and the functionalities they find important, as well as to verify the factors that determine EHR portals' adoption. Both objectives converged in the same study: *Study 3: Characterization of patient adoption of EHR Portals*. The methodology followed is subject of description in subsequent subchapter.

3.2.1. Study 3: Characterization of patient adoption of EHR Portals

With this third and last study, the aim was to achieve objectives (3) to identify the EHR portals patients are using and the functionalities they find more important and (4) to verify the determinants of adoption of EHR portals. It was determined that the strategy to approach objective (3) would be by understanding which portals patients are registered in and the functionalities they consider relevant and objective (4) was by identifying the factors influencing adoption of the portals.

The methodology chosen to design this study was natural science research methodology (March & Smith, 1995). According to the literature consulted, this methodology consists of two activities that serve the purpose of this study: *discovery* and *justification* (March & Smith, 1995).

The first - discovery - corresponds to the process of proposing scientific theories to understand reality (March & Smith, 1995). In the first endeavor of the discovery phase, the intent was to discover which EHR portals are Portuguese patients using and the functionalities they find more important, thus answering to objective (3).

The other activity of this methodology - justification - represents the processes under which the theories are tested for validity (March & Smith, 1995) and was used to achieve objective (4) to verify the determinants of adoption of EHR portals. In the context on this study, there was not a new theory proposed but the adoption of a theory described in the literature - the new research model based on the extended unified theory of acceptance and usage technology (UTAUT2) (Tavares et al., 2018; Tavares & Oliveira, 2014, 2016). This research model aims to explain patient adoption of EHR portals, by basing itself on UTAUT2 and integrating constructs related to eHealth technologies (Tavares & Oliveira, 2014). Thus, it will then be used to understand the factors that drive individuals to adopt EHR portals and provide answers to objective (4). To be highlighted that the intention was not to propose a new model nor improvements of the existing one, but to verify the statistically significant drivers already identified in the literature (Tavares et al., 2018; Tavares & Oliveira, 2014, 2016).

Having presented the theoretical support for the methodology adopted, data collection and data analysis methods are below presented separately for organization purposes, a presentation approach also found in the literature in the field (Tavares & Oliveira, 2017).

3.2.1.1. Data collection

A questionnaire was the instrument chosen to collect data to verify the determinants for adoption postulated by Tavares et al. (2018). To be noted that this approach was the one already used by the authors when proposing the model, so the questionnaire was then adapted to the constructs selected. The constructs selected were the statistically significant ones already identified by Tavares and Oliveira (2017). An introductory section of questions was added to collect socio-demographic information about the population, namely in terms of age, gender and literacy level and chronic illnesses/disability, just as Tavares and Oliveira (2016) assessed when proposing the model.

To determine which portals patients are using, a variable was designed and introduced in the questionnaire. In the format of checkboxes, the portals analyzed in study 2 were given as possible answers. This approach not only seek to identify which ones are being used, in general, but also to understand if the portals selected in study 2 are being used by patients. Another variable included in the questionnaire was one to understand which functionalities patients identify as important in EHR portals. In order words, it was made use of the potential functionalities identified in study 2, Table 3.3 (Pagliari et al., 2007), to characterize the patient's view of the same. Like this, the aim was to provide a holistic view as to assess if the functionalities offered by providers are the ones desired by patients. With the introduction of these variables the aim was then to achieve objective (3).

The items to verify the determinants of adoption - objective (4) - were adapted from other studies in the field (Tavares et al., 2018; Tavares & Oliveira, 2014, 2016), using a five-point range scale, with a range from *strongly disagree* (1) to *strongly agree* (5) or *not important* (1) to *very important* (5).

All participants were informed by introductory note on the questionnaire about the study purpose, confidentiality protection, and the anonymity of the information collected. Furthermore, before the respondents could see the questionnaire, an introduction was made describing the concept of EHR portals. The purpose of this introduction was to guarantee that respondents were conscious of the concept before answering to the questionnaire, an approach adopted from the literature (Tavares & Oliveira, 2017)

In Appendix B is presented the questionnaire that was distributed online, from beginning of July to the end of October 2018. It was created using Google® Forms and the distribution channels were academic networks such as NOVA IMS' student portal and the social networks of the author of the research, such as Facebook® and LinkedIn®. Several subsequent posts were done in the social media channels, in order to improve the response rate.

It shall be emphasized that the questionnaire by Tavares et al. (2016) was administered in English but, considering that in this study it was being submitted to the Portuguese population, and in order to maximize the number of responses, it was decided to transpose it to the Portuguese language. To be noted that professional translation services were not an option due to its expenditure, so the author translated it herself. Hence, potential translation inaccuracies of the questionnaire submitted to the population ought to be considered for this study.

3.2.1.2. Data analysis

In order to perform the statistical analysis, the tools used were Microsoft Excel® and SPSS®. For the research model, firstly the measurement model was analyzed and secondly was the structural model. For that, the partial least squares (PLS) – structural equation modelling (SEM) was relied on, a variance-based method which aims to maximize the explained variance of the latent variables (Hair, Ringle, & Sarstedt, 2011) and the software used was SmartPLS®. This method was transposed from the works of Tavares and Oliveira (2017).

4. RESULTS AND DISCUSSION

Considering the methodology described in the previous chapter, the results are presented following the same rationale, specifying the outcomes of each study designed to achieve the research objectives.

4.1. PROVIDER-CENTERED APPROACH

4.1.1. Study 1: Description of providers' view on EHR portals

4.1.1.1. Results

The intent of gathering information from healthcare providers was initiated with the selection of the ones that would be more relevant to collect data from. Considering the multiplicity of co-existing systems that characterize the Portuguese health system already described in the literature review (De Almeida et al., 2017), the research was directed to the collection of data from one or more representatives of each type of provider. Similarly to the summary of providers presented in the methodology chapter, the results are schematically presented as Table 4.1.

Table 4.1 - Interview results

Category	Provider	Status	Interviewee	Format	Length	Recording
Public	NHS	Conducted in person on March 12 th 2018	President of SPMS, E.P.E.	Combined: open-ended and interview guide	15 minutes	Audio recording and notes
Private	CUF [®]	Responded after the data collection period	N/A	N/A	N/A	N/A
	Luz [®]	No response	N/A	N/A	N/A	N/A
	Lusíadas [®]	No response	N/A	N/A	N/A	N/A
Subsystem	SAMS SBSI [®]	No response	N/A	N/A	N/A	N/A

Note. N/A = Not applicable

Having this in mind, the providers were approached in order to get the view from each on their EHR portals status and future developments. First approaches to the several entities were established during February 2018, contextualizing the research study and specifying the academical pertinence of the potential interview. From the three private healthcare units contacted, two did not give feedback to our requests for interview, despite several attempts made still during the month of March 2018. One of the private healthcare units contacted, CUF[®], replied showing availability to analyze our questions and reply to them in writing but the collection of data from this provider would be concretized much too late for the schedule of this research. The subsystem selected, SAMS SBSI[®], also did not reply to the contact. Contrarily, the public provider - Ministry of Health - via *Serviços Partilhados do Ministério da Saúde, E.P.E* (SPMS) accepted the request for interview. SPMS is, as described in the

literature review, an entity that represents the Ministry of Health, being its responsible branch for providing shared services to NHS' entities (SPMS, 2018). Among its valences is the provision and development of information and communication technologies, of which NHS' EHR portal is an example of in-house developed product (SPMS, 2018).

An in-person interview to a member of the Board of Directors took place on March 12th 2018 during approximately fifteen minutes. *A priori* designed to be based on a standardized open-ended format, the interview ended up being a combination of approaches, as a result of the fast-paced rhythm of the conversation and the interviewee openness to discuss the subjects in depth. The course of the interview was shifted to a combination of standardized open-ended questions with interview guide, a methodology described by Patton (2002). This offered the flexibility first to probe the subjects and afterwards to explore specific themes in greater depth, upon noticing the interviewee willingness to follow the same course of action. The strategy used involved then standardized open-ended questions in the early parts of the interview, posing the questions at first as specified in the interview plan. At a later part of the interview, specific subjects raised throughout the conversation were pursued, in what could be considered a guided interview (Devitt, 2003), where a list is made on the topics or subject areas to be explored in the course of the conversation but questions are not specifically determined beforehand (Devitt, 2003). To mention that despite the interview strategy being changed from the strictly standardized as described in methodology section, the approach of guided and standardized strategies combined is described by Patton (2002) as a valid and useful means to collecting qualitative data.

In order to increase the accuracy of the data collected, a mobile phone was used as recorder, as per previously agreed with the interviewee. This method of recording the verbatim allowed us to be more attentive to the interviewee and to guide the course of conversation, as suggested by Patton (2002). Nevertheless, notes were also taken throughout the interview in order to facilitate later analysis, hereafter described (Devitt, 2003).

To be noted that the full interview transcript can be found in Appendix A in the language it took place-Portuguese. Notwithstanding the transcript being considered the accurate source of the qualitative data collected (Mosley, 2012), a summary of the interview is presented hereunder in the format of principal highlights. Thus, reliability constraints of this form of results presentation are to be considered and full interview transcript is to be relied on as the ultimate solution for data verification (Mosley, 2012).

Highlight 1: NHS at different pace of ICT adoption

The first subject debated, having an introductory role in the interview, was the stand point of the NHS in terms of information systems and digital transformation. In general terms, Portugal does not stand behind other European countries in terms of digital transformation of the national health service. What is more, in some specific areas, namely electronic prescription, the Portuguese NHS stays ahead of most European countries. Regarding hospitals though, the reality is considerably heterogeneous; while some are developed in terms of information systems usage - this being true for both public and private organizations - others are still significantly paper-based and delayed to what ICT adoption is concerned.

Another challenge ahead of the NHS is the current use of information systems that are obsolete; implemented in the late 90's when the NHS first witnessed an informatization phase, some primary and secondary care units work nowadays with old systems that need modernization. Efforts are currently being made to substitute these systems, but the fact that they are used on a daily basis and the financial costs are two factors weighting in the substitution. Nevertheless, the replacement of these outdated systems is considered critical as they are technically incapable of supporting the data-privacy practices imposed by the General Data Protection Regulation (EU) 2016/679.

Highlight 2: EHR portal - one in many systems recording clinical data

The “portal do utente” is the most visible part of the electronic health record. Being a recent system ageing only five years old, it is considered a modern system to what data privacy is concerned, in the sense that gives the patient the visibility on the access history.

It was emphasized by the interviewee that the EHR portal is only one software among many others in use which record health data. For instance, an average-sized public hospital may have over thirty different information systems with clinical data stored. This being, challenges arise as one's health data is not stored in one system but in several systems, institutions, and databases. Nevertheless, the more healthcare becomes digital, the more visibility patients will have on where their health information resides.

Another relevant view is that the multiplicity of systems described poses interoperability issues when addressing the possibility of data integration. An example of that would be the fact that, some years ago, records were done without health identification number. Thus, any inaccurate data entry previously done (with regards to date of birth or name, for instance), would result in an irretrievable piece of clinical data history nowadays. This insight remarks the importance of making records robust, by having a univocal codification such as the health identification number.

Highlight 3: What to expect from EHR portal in upcoming years

When inquiring what to expect from the portal in the near future, the interviewee emphasized that having breakthrough ideas is not, nor was ever, the blocking point on the portal's development. Instead, time and resource constraints are to be pointed out as major causes slowing down the development process.

Nevertheless, an important insight conveyed is that the development of the portal should not be focused only on the introduction of new functionalities; instead a tradeoff between creating more functionalities for the portal and publicizing the existing ones to the citizens is the approach adopted. This is justified by the fact that SPMS still identifies several current functionalities as underused.

What is more, the number of new subscriptions to the portal has not witnessed an exponential increase since its creation, as it would be expected. Keeping the current pace of 1500 to 2000 new subscribers a day, NHS faces twenty years ahead to have all Portuguese citizens enrolled.

Being this considered a slow rate of adhesion, what is being done to improve it? From SPMS' point of view, introducing new functionalities is not the key to increase the number of subscribers or, at least, is not the only answer. Instead, the approach so far is to have a few very useful functionalities in which the citizen easily identifies an added value for, such as the booking of appointments. However, for that strategy to succeed, the NHS' institutions need to adapt in terms of information systems infrastructure - to interface with the portal's functionalities- but also in terms of paradigm of action – to foment digital applications rather than paper-based records.

Further to it, the idea that the success of the portal is not to be exclusively attributed to citizens was much emphasized by the interviewee, when stating that healthcare professionals should be responsible for both encouraging the use and acknowledging citizen's use. According to the representative of SPMS, professionals shall express the added value on citizens keeping their records enriched and up to date. It was emphasized by the interviewee, at this stage again, that major efforts are being made towards the digital transformation of the NHS. Specifically, a strong campaign was carried out in the months prior to the interview – called “NHS without paper”, aimed at fostering the use of NHS' digital platforms.

Still in this context, a major insight given was that the portal is more than a set of functionalities; it is the base for the digital relationship between the NHS and citizens. Hence, the major challenge towards digital transformation was said by the interviewee to be the adaptation of NHS, much more than the portal's specifications or functionalities.

Highlight 4: From young to old: a digital NHS for every citizen

Another issue addressed in the interview was the strategy being used to increase the adoption to the portal. What is then being done to achieve the goal of having all citizens enrolled in the portal?

A major challenge stepping on the way of a digital NHS is the fact that Portugal has an aged population. Since SPMS' reported goal is to have all population on the portal, regardless of age, efforts ought to be made to introduce the elderly to the digital, instead of waiting decades until generation renewal. As an example of what is being done to accomplish that, SPMS has been conducting several projects to advertise the portal, having just lately launched a new one, in Guarda district, to involve the community in the adoption of the digital platforms and decrease the use of paper. As challenging as the process can be, the involvement of civil society - via schools, associations and senior universities - is crucial to reach out to elderly citizens, as healthcare stakeholders will not be able to succeed alone.

What is more, the interviewee emphasizes that the digitalization of health services is crucial for NHS' sustainability in the long term, thus the criticality of having a digitally-empowered population.

Highlight 5: EHR beyond the citizen's portal

Although the research is mainly focused on patient's portals, questions about the expected developments for the other components of the portal were also raised. To be noted that the EHR portal developed by SPMS for the NHS comprises three other components besides the patient's: the

international, professional and institutional portals (SPMS, 2018), so the interviewee anticipated the expected evolution of each in the short-term.

For the international portal, it was expected for the pilot services to be launched still during the year of 2018. Specifically, towards the end of the summer 2018, SPMS was expecting for the exchange of information on medical prescriptions to be a possibility with Finland and Estonia.

For the professional portal, it was questioned whether it was planned for the use to be extended to non-medical personnel. Thus, the intention was to understand if the information would be made accessible to other professionals of the healthcare system, to what the interviewee clarified that it was a reality already; Pharmacists working in community pharmacies, for instance, already had access to some functionalities of the professional portal, namely to registering vaccinations administered and analytical parameters for patients with diabetes. Moreover, it was planned to extend access to data related to allergies, for instance.

For the institutional portal, a relevant insight by the interviewee was that the creation of a national repository of anonymized clinical information for scientific and epidemiological research was already envisioned and approved while ago (*RICA - Repositório de informação clínica anonimizada*, in Portuguese). Nevertheless, it is still not a reality due to lack of financial and human resources. Thus, the reason for not having open clinical data sources from the NHS is not legal nor technical; instead, constraints of investment and the lack of workforce specialized in big data are the only causes for not having yet open clinical data sources.

4.1.1.2. Discussion

Having presented the results of the interview made to the representative of the public healthcare provider, it is relevant to analyze them in the light of the results reported in the literature.

From *Highlight 1* it can be said that most of the barriers subliminally identified by the interviewee on the adoption of information systems are in accordance to what described in the literature for the specific movement of open data (Janssen et al., 2012): from the intuitional barriers that make organizations to be at different pace, to the financial barriers, similar constraints are pointed out. What is more, the task complexity as described by Janssen et al. (2012) is also emphasized by the interviewee when stating that having systems that work 24/7 pose difficulties to being replaced. An interesting finding is that, whereas in the literature the legal frameworks are considered a barrier for open data (Janssen et al., 2012), they can also be a driver of ICTs development as per the interviewee; the obligation to comply with legal requirements such as European Union's General Data Protection Regulation (EU) 2016/679 can be considered a driving force for the modernization of information systems in use in healthcare.

With regards to *Highlight 2*, it is relevant to be noted that NHS portal is acknowledged to be a relatively recent technology, insight also retrieved from the literature as the main papers found date back to the beginning of this decade (Fernandez-Aleman et al., 2013; Tavares & Oliveira, 2016). Also in line with the literature in the field is the fact that privacy is one of the main issues raised when speaking about EHR portals; from the interview it could be noticed that information privacy is taken into consideration when designing the portal and same concern is presented in the literature, as a factor influencing the adoption of EHR portals by patients (Angst & Agarwal, 2009; Tavares & Oliveira, 2014). The

interoperability challenges imposed by a complex information system architecture was referred in the interview as a barrier towards the exchange of information. Same idea is presented in literature when debating open data; under categories *task complexity* and *information quality*, Janssen et al. (2012) point out similar constraints (see Table 2.4).

From *Highlight 3*, an important insight to take out is that, despite many functionalities being identified for EHR portals (Pagliari et al., 2007), patients value some functionalities and underuse others. Likewise, papers refer that the booking of appointments and the consultation of test results are the most used features in EHR patient portals (Tavares & Oliveira, 2016), similar having been said by the interviewee. The reported efforts carried out for the modernization of NHS have also been addressed in reports published in Portugal related to health systems (Barros et al., 2011; De Almeida et al., 2017). Nevertheless, what is not clearly stated in the literature but emphasized by the interviewee is that much more is still to be done for NHS to modernize information systems and the data integration capacity.

Moving to the discussion of *Highlight 4*, the socio-economical context of Portugal is addressed as to reinforce the importance of EHR portals. Portugal's aged population (Barros et al., 2011; De Almeida et al., 2017) is to be viewed simultaneously as a challenge and as a driving force towards eHealth technologies as a whole, and towards EHR portals specifically; on one hand, the interviewee states that the elder population require more stimulus to engage on the digital. On the other hand, authors claim that EHR portals are key technologies for improving the sustainability of the health systems (Tavares & Oliveira, 2014) and that is only possible if patients, elderly inclusive, adopt EHR portals. Thus, the population need to be made literate in eHealth technologies if aiming to make healthcare systems more efficient (Ammenwerth, Schnell-Inderst, & Hoerbst, 2011; Tavares & Oliveira, 2014). The initiatives that SPMS is carrying out in interior regions of the country can be considered an example of the e-governmental strategy by the Ministry of Health.

Lastly, in *Highlight 5*, an important conclusion is that, even if the patient's portal is the most visible part of NHS' electronic health record, the other components - international portal, professional portal, and institutional portal – are not to be neglected, as part of NHS' strategy towards the integration of clinical data (SPMS, 2018). The international portal is an example of the commitment of the countries involved to having integrated strategies on information exchange, which was a trend identified when reviewing the literature (Huijboom & Broek, 2011). As for the professional portal, it is worth to note that, at the time of the interview, the available information about this component of the portal was that only doctors and nurses could access it (SPMS, 2018). This being, the opening of the portal to non-medical professionals such as pharmacists can be considered a new policy to foment health information exchange (Esmaeilzadeh & Sambasivan, 2016). What is more, the access and contributions by pharmacists can be considered a step forward on the coordination of care and improvement of patient safety, advantages identified by Esmaeilzadeh and Sambasivan (2016). Finally, with regards to the institutional portal, it can be considered the consubstantiation of governmental approach on open data, as it aims to make clinical data available for public health and epidemiological research purposes (SPMS, 2018). However, such intents face several barriers, which were already postulated by Janssen et al. (2012), namely the lack of financial resources and skillful human resources needed for such a complex and demanding task in terms of technological infrastructure (Hossain et al., 2016; Janssen et al., 2012). Also, to be noticed that the possible barriers on open data are usually interrelated and likely

to be verified together – not having financial resources is a cause of not being able to recruit experts which correspond to the findings by Janssen et al. (2012).

Figure 4.1 represents the *word cloud* of the transcript of the interview, insighting that the keywords were *digital, people, data* and *portal*, much in line with the keywords found in the literature for papers in the field (Cochran et al., 2015; Khan & Hoque, 2016; Tavares et al., 2018; Tavares & Oliveira, 2014, 2016).



Figure 4.1 - *Word Cloud* of interview transcript

4.1.2. Study 2: Comparative analysis of EHR portals' functionalities

The second study carried out aimed at identifying the functionalities offered by the portals from the same providers approached for interview in study 1. As described in the methodology chapter, the assessment of functionalities was based on the research work by Pagliari, Detmer and Singleton (2007), whom proposed the potential functions of EHR's. The collection of data was performed during June 2018 and the results are presented qualitatively, with "Y", i.e. "Yes", meaning the portal has the functionality or "N", i.e. "No" meaning the portal does not present the functionality.

To be noted that the level of development of each functionality or its usability was not quantitatively assessed, thus leaving room for, in this context, classifying equally functionalities at distinct stages of development. Nevertheless, when comparing the functionalities between portals, it may be highlighted the particular differences between them for one's better understanding, rather than being an objective of this study.

For a better organization of the results, they are hereby presented in the format of four separate tables: Table 4.2 - Results Observed for the Portals for Functionalities "Access to provider's EHR" and "Personal health organizer", Table 4.3 - Results observed for the portals for functionalities "Self-management support" and "Communication", Table 4.4 - Results Observed for the Portals for

Functionalities “Information Repository” and “Sources of support” and Table 4.5 - Results Observed for the Portals for Functionality “Capture of symptoms or health behavior data”.

4.1.2.1. Results

In Table 4.2 are presented the results of the five portals when assessed in terms of “access to provider's EHR” and as “personal health organizer”.

With regards to functionality “access to provider’s EHR”, the "Portal do utente" from NHS and "O Meu Portal" from Hospitals/Clinics Lusíadas® are the only ones that present all the functionalities. "Portal do utente" provides the clinical history via the view of the interactions made with NHS but without further detailing the clinical outputs of it. It also offers the possibility to access test results and last prescriptions. With regards to medication, it gives the citizen an active role of recording chronic medication information. Similarly, "O Meu Portal" from Hospitals/Clinics Lusíadas® also presents the history of clinical interactions with the provider but with no clinical details. Lusíadas® portal also provides de visibility on test results and medication prescribed. Nevertheless, it does not give the possibility of self-recording clinical information. The "Portal do Cliente" from Hospitals/Clinics Luz® and "MyCUF" from Hospitals/Clinics CUF® present all the sub-functionalities in the category but the access to medication; they provide though information about the clinical interactions with the institution and exams results. The portal "MySAMS" from Hospitals/Clinics SAMS SBSI® does not present any of the sub-functionalities on this category.

About the functionality “personal health organizer”, all portals analyzed present the sub-functionalities with two observations worth to be remarked: (1) the clinical agenda is offered by all, giving the consumer a personal health diary to manage upcoming appointments and (2) except for the NHS portal in which a consumer has his primary-care doctor as assistant doctor (in Portuguese called “médico de família”), the other portals give the possibility of choosing a doctor, depending on the appointment. Nevertheless, it was considered that all the portals had the functionality of “assistant doctor” in the sense that they give the consumer the visibility on the physician in charge of the clinical interaction. Also, criteria to verify the presence of this feature was not found in the framework proposed by Pagliari et al. (2007) or any other literature. Thus, it was considered verified for all portals, highlighting though the limitation of not knowing if the criteria to verify this sub-functionality is the visibility or the choice of the assistant doctor.

From these first functionalities analyzed, two general insights can be drawn; the first being the fact that “Portal do utente” from NHS and "O Meu Portal" from Hospitals/Clinics Lusíadas® are the only ones presenting all the functionalities, whereas "Portal do Cliente" from Hospitals/Clinics Luz and "MyCUF" from Hospitals/Clinics CUF® lack one functionality each. The second insight is that "MySAMS" from Hospitals/Clinics SAMS SBSI® only presents two out of the five functionalities analyzed, corresponding to the ones of “personal health organizer”.

Table 4.2 - Results Observed for the Portals for Functionalities “Access to provider's EHR” and “Personal health organizer”

Functionality	Access to provider's EHR			Personal health organizer	
Sub-Functionality	Clinical history	Test results	Medication	Clinical agenda	Assistant doctor

"Portal do utente" from NHS	Y	Y	Y	Y	Y
"O Meu Portal" from Hospitals/Clinics Lusíadas®	Y	Y	Y	Y	Y
"Portal do Cliente" from Hospitals/Clinics Luz®	Y	Y	N	Y	Y
"MyCUF" from Hospitals/Clinics CUF®	Y	Y	N	Y	Y
"MySAMS" from Hospitals/Clinics SAMS SBSI®	N	N	N	Y	Y

Note. Y = Yes, the portal presents the functionality. N = No, the portal does not present the functionality.

Moving on to the features of “self-management support” and “communication” (see Table 4.3), it was observed that there are less number of positive observations if comparing with the previous functionalities. Regarding the “self-management support”, it was registered only one positive observation on the “care plans” by "Portal do utente" from NHS. It was concluded that this is the only portal among the ones analyzed that provides care plans to the consumers via several valences, namely an individual healthcare plan and a diabetes risk assessment. Nevertheless, even in NHS’ portal it is present a disclaimer stating that this functionality is still under development and that pilot tests are in progress, leading to conclude that this feature is not present on any private-provider portal and in experimental phase in the public-provider portal. Notwithstanding, it was considered as a “Y” for NHS. The sub-functionalities of “graphing of symptoms” and “customized instructive or motivational feedback” were not observed in any of the portals.

Within functionality “communication”, the sub-functionality “booking of appointments” is available in all the portals, enabling the consumer to schedule medical acts. Once again, it is noticeable a difference between the public and the private providers: on NHS the consumers can only schedule an appointment with his primary-care doctor whereas on private portals it is possible to choose a medical specialty and a specific doctor. The sub-functionality “reordering prescriptions” is present only in "Portal do utente" from NHS for users identified as taking chronic medication. Portals like "O Meu Portal" from Hospitals/Clinics Lusíadas® provide access to the prescriptions made but do not allow to request prescription renewals. Regarding the last sub-functionality in this category, “Seek advice (eg patient-doctor email)”, it was noted that none of the portals present it; all of them offer the consumer the possibility to make an institutional email contact but do not allow to write directly to the physician.

To note then that all the portals but "Portal do utente" from NHS present only one sub-functionality among the ones presented in Table 4.3-, the “booking appointments”.

Table 4.3 - Results observed for the portals for functionalities “Self-management support” and “Communication”

Functionality	Self-management support			Communication		
	Sub-Functionality	Care Plans	Graphing of symptoms	Customized instructive or motivational feedback	Booking appointments	Reordering prescriptions
"Portal do utente" from NHS	Y	N	N	Y	Y	N
"O Meu Portal" from Hospitals/Clinics Lusíadas®	N	N	N	Y	N	N
"Portal do Cliente" from Hospitals/Clinics Luz®	N	N	N	Y	N	N
"MyCUF" from Hospitals/Clinics CUF®	N	N	N	Y	N	N
"MySAMS" from Hospitals/Clinics SAMS SBSI®	N	N	N	Y	N	N

Note. Y = Yes, the portal presents the functionality. N = No, the portal does not present the functionality.

Other functionalities analyzed were "information repository" and "sources of support" (see Table 4.4) having observed that the "Portal do utente" from NHS is the only one that presented features in these categories.

Concerning "information repository", NHS' is the only portal which actually has it embedded. Via its online library on health literacy, NHS' portal is a source of information on treatments and self-care, thus fulfilling two out of three sub-functionalities in this category; it presents information about health education and healthy lifestyle in different formats such as videos, brochures and books.

To be noted that NHS does not only provide resources of its own, but it also compiles health information produced by other entities such as the *National Authority of Medicines and Health Products* (Infarmed, I.P.) or the *National Association of Pharmacies*. Nevertheless, the selection and eligibility criteria to be published on the platform is on the solely discretion of the NHS (SPMS, 2018). Due to the resources not being related to specific illnesses *per se* but having to do with the importance of an active life and the promotion of health, "Portal do utente" from NHS was not considered as presenting sub-functionality "about illnesses". Nevertheless, it shall be emphasized that the intention to expand the content of the library to illnesses was clearly stated in the platform. As for the other portals observed, to note that none presented any sub-functionality of "information repository".

With regards to functionality "sources of support", no portal presented any of its sub-functionalities except NHS' portal. This one was considered to have sub-functionality "patients

organizations/associations” as, via the online library, users are redirected to contents and resources from associations such as *Associação Portuguesa de Apoio à Vítima* or *Associação Alzheimer Portugal – Associação Portuguesa de Familiares e Amigos dos Doentes de Alzheimer*. On the other hand, none was considered to have sub-functionality “virtual peer networks” as in the extensive exploration of the portals it was not found any functionality such as forums nor links to external patient networks.

Table 4.4 - Results Observed for the Portals for Functionalities “Information Repository” and “Sources of support”

Functionality	Information Repository			Sources of support	
	Sub-Functionality	About illnesses	About treatments	About self-care	Patients organizations/associations
"Portal do utente" from NHS	N	Y	Y	Y	N
"O Meu Portal" from Hospitals/Clinics Lusíadas®	N	N	N	N	N
"Portal do Cliente" from Hospitals/Clinics Luz®	N	N	N	N	N
"MyCUF" from Hospitals/Clinics CUF®	N	N	N	N	N
"MySAMS" from Hospitals/Clinics SAMS SBSI®	N	N	N	N	N

Note. Y = Yes, the portal presents the functionality. N = No, the portal does not present the functionality.

A last potential functionality of EHR portals suggested by Pagliari et al. (2007) is the “capture of symptom or health behavior data”, having observed that NHS’ portal is the only presenting one of the sub-functionalities, as allowing the patient to register health parameters such as weight or allergies.

Table 4.5 - Results Observed for the Portals for Functionality “Capture of symptoms or health behavior data”

Functionality	Capture of symptoms or health behavior data	
	Sub-Functionality	Via self-report
"Portal do utente" from NHS	Y	N
"O Meu Portal" from Hospitals/Clinics Lusíadas®	N	N

"Portal do Cliente" from Hospitals/Clinics Luz®	N	N
"MyCUF" from Hospitals/Clinics CUF®	N	N
"MySAMS" from Hospitals/Clinics SAMS SBSI®	N	N

Note. Y = Yes, the portal presents the functionality. N = No, the portal does not present the functionality.

4.1.2.2. Discussion

Presented that are the results of the observational study, it is relevant to draw the major findings of it. To highlight, first of all, that none of the portals analyzed presented all the functionalities suggested by Pagliari et al. (2007) but, on the other hand, none lacked all of the features.

It is also worth to retain that the "Portal do utente" from NHS was the one presenting more functionalities (12 out of a total 17) and that portal "MySAMS" from Hospitals/Clinics SAMS SBSI® was the one presenting the least number of functionalities (3 out of 17). In between in terms of number of functionalities there are the portals from the private providers: "O Meu Portal" from Hospitals/Clinics Lusíadas® (6 out of 17), "Portal do Cliente" from Hospitals/Clinics Luz® (5 out of 17) and "MyCUF" from Hospitals/Clinics CUF® (5 out of 17).

Not only NHS' portal is the one presenting an overall bigger number of functionalities, but it is also the only one registering at least one functionality of each category, which can support its classification as the most complete and versatile portal among the ones analyzed.

Considering that portals such as "MySAMS" presented few number of functionalities, the literature was searched to understand if there were a minimum number of functionalities or if there were mandatory functionalities for an EHR portal to be considered as such but no guideline was found on it, nor in Pagliari et al. (2007) framework, nor in any other research works in the field (Kim & Johnson, 2002). This leads to pointing out that further research is recommended to determine the minimum requirements for a platform to be considered an Electronic Health Record Portal.

What is more, it can be noticed that there are functionalities that all or most of the portals present such as "clinical agenda" and "booking appointments" whereas others like "graphing of symptoms" or "patient-doctor email" are not affixed by any of the providers. Again, as not found in the literature (Kim & Johnson, 2002; Pagliari et al., 2007), it is identified that further research is needed to determine which are the basic functionalities of a portal and which could be considered secondary.

Another relevant insight to make is that there may be strategical decisions for the private and sub-system providers not having more functionalities on the portal; recalling that the approach by the public provider - as identified in study 1 - was to bet on having some very relevant functionalities rather than developing all functionalities possible, it can be hypothesized that the rationale also applies to the other portals besides NHS'. This hypothesis could not be verified since it was not possible to collect the perspective of non-NHS providers when carrying out study 1, but it can be observed that all the portals have functionalities as "booking appointments", identified as important and useful by the public provider.

Lastly, it should be highlighted that this observational study took place during a specific period of time - June 2018 – meaning that the results should be framed accordingly. As identified for NHS’ portal previously in study 1, portals are being evolved and developed and the functionalities by them presented are understandably not stanch. Thus, the results in this study presented should be considered for the period they were observed.

4.2. PATIENT-CENTERED APPROACH

4.2.1. Study 3: Characterization of patient adoption of EHR Portals

The third and last study of the research aimed at, on one side to understand which portals patients are using and the functionalities they look for – objective (3) - and on the other side to verify the determinants of EHR portals adoption – objective (4). Eighty-one valid responses to the questionnaire were collected. To be noted that, unlike previous studies, results and discussion are presented together for study 3.

Because the same method of data collection was used to address both objectives, the results presentation is divided into several subchapters for organization purposes: in 4.2.1.1 not only the socio-demographic characteristics of the sample are presented but also the variables designed to answer to objective (3) and in 4.2.1.2 and 4.2.1.3 the results of the research model used are detailed, namely the measurement model and the structural model respectively. Prior to that, though, the research model used is hereby presented and theoretically justified, as well as the hypotheses tested.

Starting by the model used, UTAUT2, literature hinted that it was broadly implemented in patient-centered eHealth tools due to including specific constructs, relevant for the study of the adoption of EHR portals (Tavares et al., 2018; Tavares & Oliveira, 2014, 2017). Despite Tavares and Oliveira (2017) suggesting a complex model of twelve literature-based hypotheses, the hypotheses in this study verified were four, which can be attributed to the small number of responses to the questionnaire.

The formulated hypotheses verified were the following:

Performance expectancy is defined as the degree to which using a technology will provide benefits to consumers in carrying out certain activities (Tavares & Oliveira, 2016, 2017). Literature indicates that healthcare consumers tend to adopt more eHealth technologies that provide clear benefits, such as obtaining an electronic medical prescription via EHR portals (Tavares & Oliveira, 2016). Therefore, it is hypothesized that:

Hypothesis 1 (H1): performance expectancy positively influences behavioral intention

Habit can be defined as the extent to which people tend to execute behaviors automatically because of learning (Tavares & Oliveira, 2016, 2017). Previous studies showed that habit positively influences eHealth adoption (Tavares & Oliveira, 2017). Therefore, it is hypothesized that:

Hypothesis 2 (H2) Habit positively influences behavioral intention

Hypothesis 3 (H3) Habit positively influences use Behavior

The role of behavioral intention as a predictor of use behavior has been established for eHealth technologies, with the literature suggesting that the driver of using eHealth tools in general and EHR portals in particular is preceded by the behavior intention to use them (Tavares & Oliveira, 2017). Therefore, it is hypothesized that:

Hypothesis 4 (H4): behavioral Intention will positively influence use behavior

Figure 4.2 schematizes the research model verified, showing the relationships of constructs – PE, HT, BI and UB – and hypotheses – H1, H2, H3 and H4.

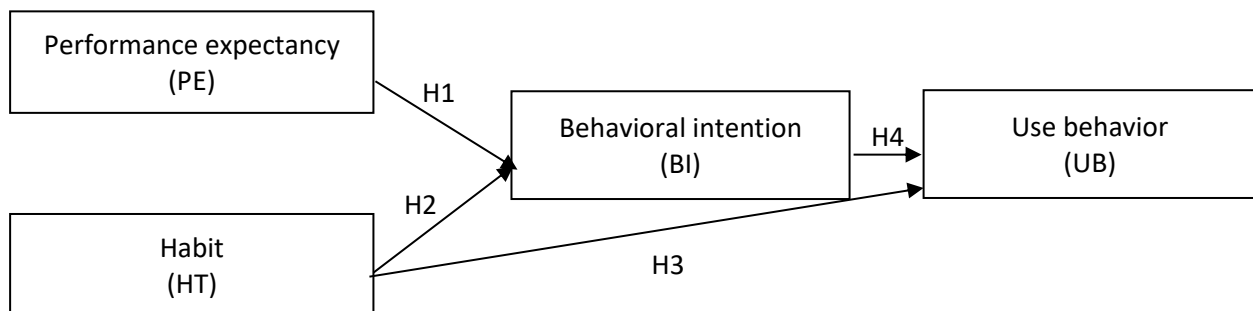


Figure 4.2 - Research model used verified, adapted from the new research model based on the unified theory of acceptance and use of technology in a consumer context (UTAUT2) (Tavares et al., 2018; Tavares & Oliveira, 2014, 2016, 2017)

4.2.1.1. Sample characteristics

In this subchapter, the statistical analysis of the sample is presented as well as the results of the variables introduced in the questionnaire to answer objective (3).

Starting by the statistical analysis, in Table 4.6, the frequencies and average of variable “Age” are presented. It can be noticed that the average is 35.43 years and the mode is the interval [31-40] years. In the literature it is stated that users of EHR portals are younger than the population, thus the results shown in Table 4.6 are in line with literature findings (Tavares & Oliveira, 2016, 2017). Nevertheless, it must be noted that the questionnaire was mostly distributed in NOVA IMS’ student portal and through the author’s network, whom are mainly *millennials* and may not be representative of the Portuguese population for this variable.

Table 4.6 - Sample characteristics for variable “Age”

Variable	Frequency, n (%)	Average
Age in years		
[18-20]	1 (1.23)	35.43
[21-24]	9 (11.11)	
[25-30]	22 (27.16)	
[31-40]	27 (33.33)	

With regards to variable “Gender”, there was a higher level of responses by female individuals, as per the frequencies registered (see Table 4.7), which is in line with the statistics of the Portuguese population according to which there is a higher number of women than men (Santos, 2018).

Table 4.7 - Sample characteristics for variable “Gender”

Variable	Frequency, n (%)
Gender	
Male	36 (44.44)
Female	45 (55.56)

About variable “Education”, the frequencies and percentages are shown in Table 4.8, per education level. The majority of the people who responded to the questionnaire were postgraduates. Literature referred that most users of EHR portals have higher education, finding these results are in line with (Tavares & Oliveira, 2017). Again, it ought to be considered that the questionnaire’s distribution channels might have imposed bias on this variable as it was publicized in an academical context.

Table 4.8 - Sample characteristics for variable “Education”

Variable	Frequency, n (%)
Education	
Basic Education	3 (3.70)
High school	10 (12.35)
Undergraduate	21 (25.93)
Bachelor’s degree	1 (1.23)
Postgraduate	26 (32.10)
Master’s degree or more	20 (24.69)

Concerning variable “Chronic illness/disability”, it is worth to be noted that in the literature it is defined as an incapacitating situation that affects a patient permanently or for long periods of time (Tavares & Oliveira, 2016). Research in the field revealed that patients with chronic illness or disability are more likely to use eHealth technologies (Tavares & Oliveira, 2016). However, such hypothesis was not verified as the number of responses obtained is considered low for that verification. Despite not verifying the hypotheses, this variable can be considered for sample characterization. Table 4.9 shows the results breakdown for this variable, with more that 80% of the users not presenting any chronic condition.

Table 4.9 - Sample characteristics for variable “Chronic illness/disability”

Variable	Frequency, n (%)
Chronic illness/disability	
Yes	15 (18.52)
No	66 (81.48)

Next, in Figure 4.3, are presented the results of variable “Knowledge of EHR portals”. Twenty-seven users self-evaluated their knowledge as median in the five-point range scale, equivalent to 33.33% of the sample. Only four people (4.9%) claimed to have strong knowledge of EHR portals. Studies that assessed this variable were not found in the literature, but this finding is in line with study 1, as publicizing and strengthening the knowledge on NHS’ EHR portal was identified by the representative of SPMS as a priority. Thus, it can be said that much is yet to be done to make users knowledgeable on EHR portals.

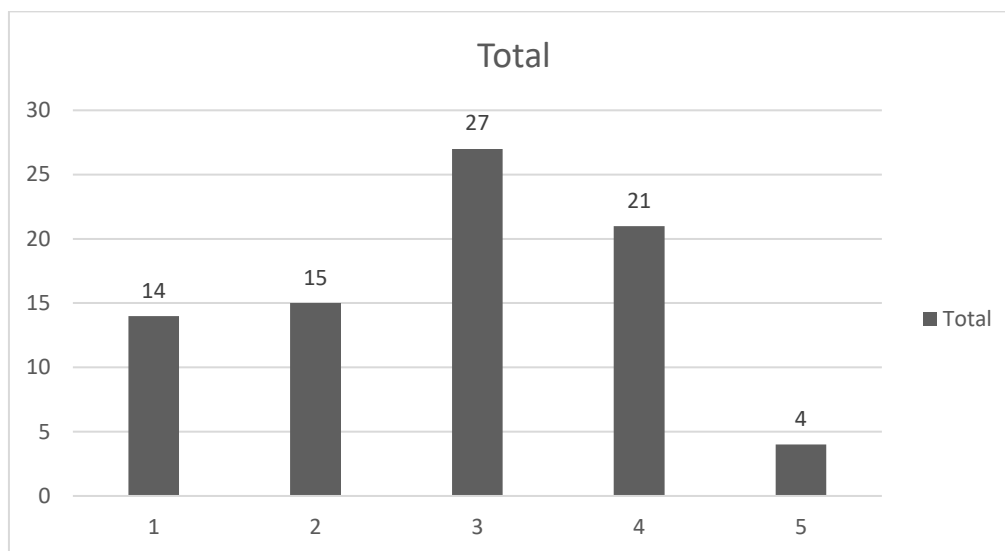


Figure 4.3 - Results for variable “Knowledge of EHR portals”

The variables analyzed before can be considered to have characterized the sample but, as presented in the methodology, two more variables were introduced to achieve objective (3).

The first one - “EHR portals in use” - was designed to assess which portals, among the ones selected for studies 1 and 2, have users subscribed so far. It can be concluded that almost half of the users (49.38%) who responded are already subscribers of NHS’ portal (see Table 4.10). Considering that, as mentioned in study 1, NHS aims to have all Portuguese population on the portal regardless of age, it can be said that more efforts shall yet be made.

Among the private providers, CUF® is the one having more users signed in (11.11%). The users of private providers’ portals are much less than NHS’ but these results have to be framed by the fact that NHS has universal coverage, whereas private healthcare is accessible to 10% of the population only, as of 2006 (Barros et al., 2011; De Almeida et al., 2017).

The subsystem is the one having less subscribers in the sample which is in line with its universe, as the access is limited to members of a specific profession and their families and not to the entire population

(Barros et al., 2011; De Almeida et al., 2017). Nevertheless, data on the number of people covered by SAMS SBSI® was not found in the literature so it was not possible to contextualize the results verified with the percentage of the universe that has access to this subsystem.

To be highlighted that 25.93% of the sample did not respond to the portals their using which may indicate that they are not using any. Nevertheless, it is not a certainty as it can also be considered that people chose not to reply to this question, as it was not a mandatory one in the questionnaire. No studies were found in the literature that assessed this variable, so comparison of results was not possible to make.

Table 4.10 - Results for variable “EHR portals in use”

Category	Variable	Frequency, n (%)
EHR portals in use		
Public	"Portal do utente" from NHS	40 (49.38)
Private	"O Meu Portal" from Hospitais/Clínicas Lusíadas®	3 (3.70)
	"Portal do Cliente" from Hospitais/Clínicas da Luz®	7 (8.64)
	"MyCUF" from Hospitais/Clínicas CUF®	9 (11.11)
Subsystem	"MySAMS" from Hospitais/Clínicas SAMS SBSI®	1 (1.23)
	Blanks / Not responded	21 (25.93)

The second variable which aimed to give answers to objective (3) was “Most important functionalities”. Results found let to conclude that users identify some functionalities as more important than others (see Figure 4.4). More specifically, “access to provider's EHR” and “communication” are the ones identified as more important, with more than half users classifying it with the maximum of importance in the five-point scale (48 out of 81 and 42 out of 81, respectively). The other functionalities are considered to have some importance - very few users considered them to have no importance - but have comparably less importance than the two mentioned before. For instance, the functionalities “source of support” and “capture of symptoms or health behavior data” can be said to be less important to users, with 21 and 13, respectively, out of 81 users attributing it the lower levels “1” and “2” of the scale. An interesting insight still from the study of this variable is with regards to functionality “self-management support” which registered most observations around median, in practical terms meaning that users do not consider it a very important functionality but, at the same time, it is not totally unvalued.

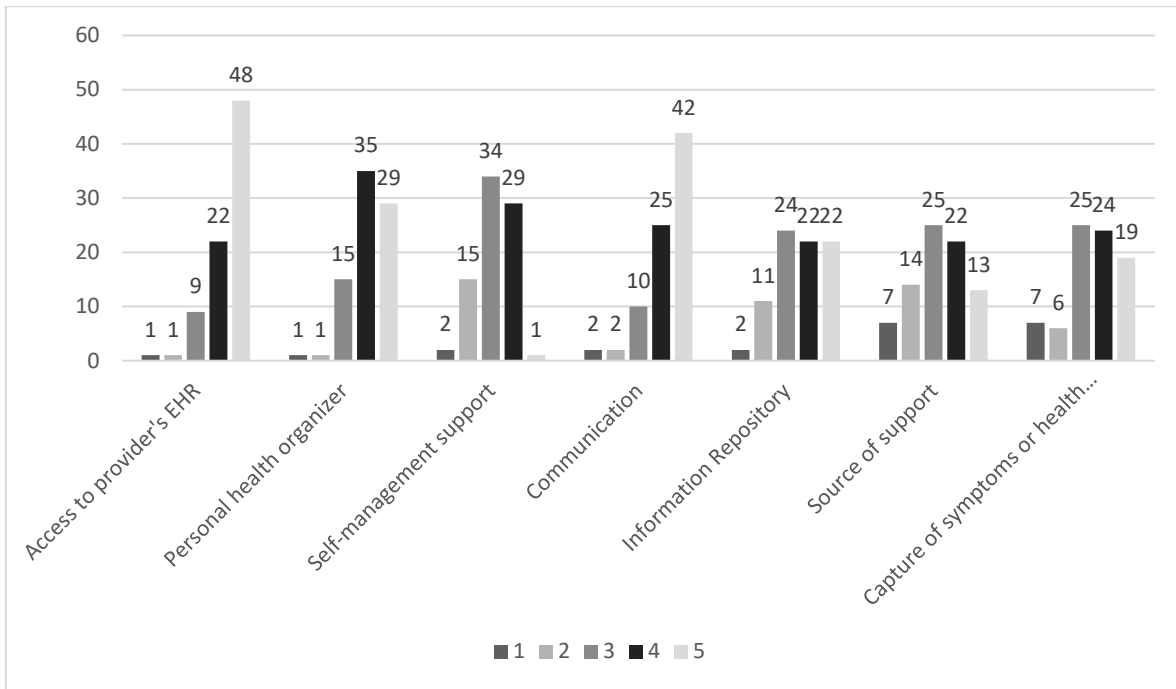


Figure 4.4 - Results for variable “Most important functionalities”

These results are in line with the ones presented in study 1 in the sense that the interviewee pointed out that, as from SPMS’ knowledge, users indeed see an added value in some functionalities and those are the ones that SPMS seeks to develop the most. What is more, from study 2 it can be said that portals present some of the functionalities identified as important by the users but not all. For instance, “access to provider's EHR” is not offered by SAMS SBSI®’s portal. About “communication” functionality, it was concluded from study 2 that all portals offered the sub-functionality “booking appointments” but failed to have the other two sub-functionalities. As this research only evaluated the importance of the major functionalities, further research would be relevant as to identify the specific sub-functionalities valued by users. Nevertheless, it has the potential of giving insights for providers to meet user’s demands when developing the portals.

Again, as for the previous variable, no information was found in the literature to compare this results with.

4.2.1.2. Measurement Model

The measurement model results are shown in Table 4.11, where Cronbach’s alpha is presented. This is the criterion used to evaluate construct reliability, as per the literature consulted, and it assumes that all the indicators are equally reliable (Hair, Hult, Ringle, & Sarstedt, 2014). However, composite reliability coefficient is more appropriate for the method used (PLS-SEM) because it ranks indicators according to their individual reliability and also takes into account that indicators have different loadings, unlike Cronbach’s alpha (Hair et al., 2014). Table 4.11 shows that the constructs have composite reliability higher than 0.70, demonstrating evidence of internal consistency, as per the literature (Hair et al., 2014). In order to assess the convergent validity, the average variance extracted

was used, which should be greater than 0.50 to explain more than half of the variance of its own indicators (Hair et al., 2014). As per the results in Table 4.11, all the indicators respect this criterion.

Table 4.11 - Cronbach's alpha, composite reliability, and average variance extracted

Constructs	Cronbach's Alpha	Composite Reliability	Average Variance Extracted
Use behavior	1	1	1
Performance expectancy	0.864	0.916	0.784
Habit	0.947	0.966	0.904
Behavioral intention	0.926	0.953	0.871

Another measure assessed was the discriminant validity. It is defined as the degree of distinction of the several constructs in the model (Hair et al., 2014). Two measures of discriminant validity can be used: by *Fornell- Larcker* criterion or by the cross loadings of the indicators (Tavares & Oliveira, 2017), According to this last criterion, considered as a more liberal than *Fornell- Larcker's*, an indicator loading should be higher on the associated construct than all of its loadings in the other constructs (Hair et al., 2014). This criterion then met, as seen in Table 4.12, thus attesting the discriminant validity of the model.

Table 4.12 - Cross Loadings

Cross Loadings	Constructs			
	Behavioral intention	Habit	Performance expectancy	Use behavior
BI1	0.911	0.348	0.355	0.5471
BI2	0.934	0.416	0.293	0.491
BI3	0.955	0.411	0.305	0.515
HT1	0.454	0.937	0.239	0.674
HT2	0.38	0.965	0.205	0.566
HT3	0.35	0.95	0.214	0.578
PE1	0.231	0.167	0.844	0.049
PE2	0.304	0.17	0.91	0.175
PE3	0.35	0.264	0.901	0.229
UB1	0.555	0.642	0.184	1

4.2.1.3. Structural Model

With regards to the structural model path, the R^2 was used to assess it, in line to what described in the literature (Hair et al., 2014). The overall results show that the model explains 24% of the variance in behavioral intention and 51% of the variance in use behavior (see Figure 4.5).

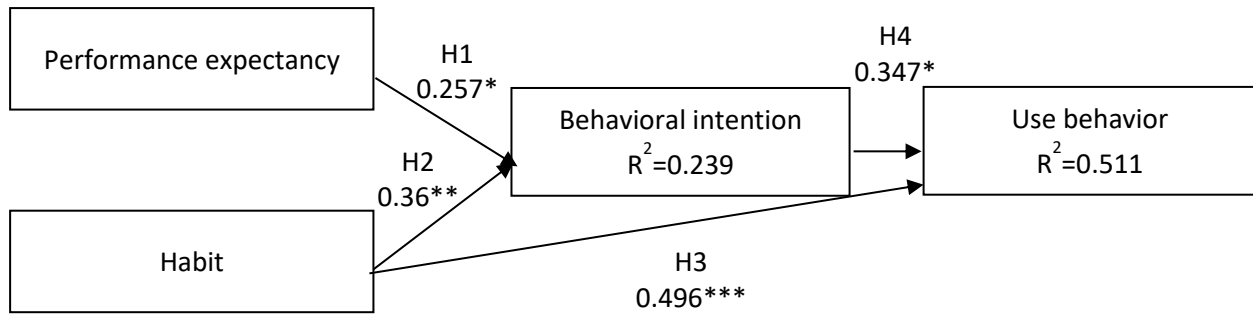


Figure 4.5 - Structural model

In Table 4.13 are summarized the findings regarding hypotheses. *Hypothesis 1* and *Hypothesis 2* were supported which means that performance expectancy (beta=0.2257; t=2.619) and habit (beta =0.6; t=2.747) are the predictors of behavioral intention. The predictors of technology use behavior are habit (beta =0.496; t=4.628) and behavioral intention (beta =0.347; t=2.455), thus supporting *Hypothesis 3* and *Hypothesis 4*, respectively.

Table 4.13 - Summary of findings regarding hypotheses

Hypotheses	Beta	t-value	p value	
H1	0.257	2,619	0.014	*
H2	0.36	2,747	0.006	**
H3	0.496	4,628	0	***
H4	0.347	2,455	0.014	*

Note. Significant for * $p < 0.05$, ** $p < 0.01$, *** $p < 0.001$

Summing up the principal results of the research model, it was considered to present good results as it explains 24% and 51% of the variance in behavioral intention and use behavior, respectively. The most important contributors impacting behavioral intention are performance expectancy and habit, whereas the predictors of use behavior are habit and behavioral intention. These results are in line with the literature (Tavares & Oliveira, 2016, 2017); the level of performance expectancy influences in a positive way the intention to use of health portals, and the habit also has a positive impact on the intention to use of this kind of portals. From this study, it can also be demonstrated that intention to use health portals have a positive impact on the usage itself.(Tavares et al., 2018; Tavares & Oliveira, 2014, 2016, 2017).

Overall, the model was able to demonstrate three constructs that are important for the understanding of the adoption of EHR portals: *performance expectancy*, *habit* and *behavioral intention*.

5. CONCLUSIONS, LIMITATIONS AND RECOMMENDATIONS FOR FUTURE WORKS

EHR portals are applications that can greatly benefit healthcare delivery for both providers and patients. On the provider's side, it is considered as a base for a safer and more efficient healthcare system. On the patient's side, it allows patients an active role on their health data management, thus contributing to citizen empowerment. Thus, the aim of this research was to characterize the view on EHR portals from both these stakeholders' perspective.

From the providers, it became clear that EHR portals are faced as important platforms that contribute to the digital transformation of the National Health Service. Despite the recognized importance of EHR portals, the number of users is still far below target – which for NHS, being a universal system, the target is to have all Portuguese population subscribing and actively using the portal. Therefore, much is still to be accomplished from the NHS to succeed and to have the capacity of adaptation in terms of information systems infrastructure was identified as crucial. It was also possible to conclude that the portals offered by the major providers of healthcare services in Portugal are very heterogeneous in terms of functionalities; on one hand there are functionalities present on most of them, indicating that those could be the one considered more important by the providers but on the other hand, some functionalities are not verifiable on the majority of the portals, hinting that they are considered as secondary by the providers.

From the patient side, it was possible to conclude that almost half of the users inquired are using NHS' portal and very few are subscribers of the portals offered by private providers as CUF®, Luz® and Lusíadas® or subsystems as SAMS SBSI®. Also, it was possible to notice that patients consider the functionalities of the portals to have different level of importance, being the access to the providers' records and the possibility to have a communication channel identified as the most important. At last, it was concluded that the determinants of the adoption of EHR portals are behavioral intention and habit, with behavioral intentional being in its turn determined by habit and performance expectancy.

Being a research that addresses an important topic such as EHR portals with an holistic approach of provider and patient views, managerial insights that can be helpful in the design and implementation of this specific technology are expected to be provided. A relevant implication of this study was that EHR portals should be considered by healthcare providers as the base for the aimed digital relationship with patients. Because providers should meet patients' needs if intending to engage them on EHR portals, this study also contributed to assess if the functionalities offered are the ones that patients value more and how do each portal compares with its competitors'. At last, by identifying the determinants of adoption, this study has the potential of aiding providers to design EHR portals that can give patients an active role in their healthcare management, while improving efficiency of healthcare delivery.

This research faced some limitations that should be mentioned. First, in the scope of study 1, it was not possible to collect information from the several providers, thus limiting the view from providers to only the public NHS. Secondly, in study 2 the assessment of portals was only qualitative, hence not considering that some portals may have different levels of development of the same functionality that could be worth being emphasized. Also, the number of portals analyzed did not cover all the providers in Portugal and, especially for subsystems, the sample may not be representative as only one was

assessed. Third, in study 3, the number of responses is considered very low to verify the statistical significance of the variables selected beforehand. What is more, the constructs transposed to the questionnaire were only the ones previously identified in the literature as statistically significant, narrowing down the scope of the research model adopted. At last, there is a linguistic barrier implicitly associated to studies 1 and 3, as the interview and questionnaire, respectively, were designed and carried out in Portuguese and transposed to English to be presented in this research. Thus, inaccuracies of translation must be considered when addressing the results and discussion of those studies.

The need for future research works became apparent as to have a broader assessment of the providers view on EHR portals but also to analyze the functionalities of each portal in depth, with a quantitative approach that could include usability metrics. Also, it would be relevant to retake study 3 to have for responses to the questionnaire and to assess all the determinants of adoption proposed in the literature. Lastly, it would be relevant to address the problematic of EHR portals from the perspective of more stakeholders besides providers and patients.

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APPENDIX A

STRUCTURE OF THE OPEN-ENDED INTERVIEW DESIGNED FOR STUDY 1

“Nota introdutória:

O presente questionário está integrado no âmbito da tese de Mestrado de Gestão de Informação e *Business Intelligence* da NOVA IMS.

- (1) De acordo com a estratégia de informatização clínica do SNS, definida pelo Ministério da Saúde, a SPMS tem desenvolvido vários produtos. Em que patamar considera que o SNS se encontra em matéria de tecnologias de informação aplicadas à saúde e na transformação digital?
- (2) Quais são os principais desafios e necessidades em termos de registos eletrónicos no SNS?
- (3) O RSE- Registo de Saúde Eletrónico na vertente destinada ao cidadão – Área do Cidadão – visa dar-lhe um papel ativo na manutenção e promoção da sua saúde. São vários os serviços eletrónicos disponíveis no portal (registo de medições, marcação de consultas). O que esperar nos próximos anos da evolução portal?
- (4) Estão previstos novos serviços/funcionalidades para o portal?
- (5) Outra das vertentes do RSE é o portal do profissional. Será de esperar que nos próximos anos o portal seja acessível a prestadores não-SNS (e.g. Farmácias)?
- (6) Outra das vertentes do RSE é o portal do Internacional. Em que fase se encontra este projeto? Já é uma realidade a acessibilidade do resumo clínico do utente em toda a UE?
- (7) Quais são os principais desafios e barreiras na partilha de dados no SNS?
- (8) O uso de dados de saúde para fins não -clínicos (i.e. uso secundário) tem o potencial de fomentar o conhecimento científico, melhorar a performance dos sistemas de saúde e avaliar impactos em saúde pública (Safran et al., 2007). No SNS, o uso dos dados clínicos para fins secundários é uma realidade? Se sim, em que trâmites?
- (9) Entre as maiores barreiras na partilha de dados estão a qualidade da informação e incompatibilidades técnicas dos sistemas (Janssen et al., 2012)? Saber-nos-á descrever em que fase estão estas iniciativas, nomeadamente em que ponto nos encontramos na interoperabilidade técnica dos sistemas?
- (10) A privacidade e proteção de dados é uma das maiores preocupações em saúde (Malin, Emam, & O’Keefe, 2013). De que forma o Regulamento Geral de Proteção de Dados, a entrar em vigor este ano, tem impactado a gestão dos sistemas de informação em saúde?
- (11) Sabe dizer-nos de que forma os sistemas de informação estão a ser desenvolvidos para capacitar as entidades SNS a cumprir com os requisitos do Regulamento Geral de Proteção de Dados?
- (12) De que forma é que as entidades e profissionais SNS estão a ser capacitados para o cumprimento do RGPD. Sabemos que foi elaborado um guia sobre o Regulamento Geral de Proteção de Dados mas existem equipas a diagnosticar e acompanhar a implementação?
- (13) Que desafios representa o RGPD à partilha de dados em saúde e ao uso secundário dos dados? Poderá o RGPD ser uma barreira?
- (14) Por último, a SPMS é responsável por iniciativas como o ‘Portal da Transparência’ que disponibiliza em tempo real e de forma aberta dados sobre o SNS. De que forma está previsto que as iniciativas *open data* possam evoluir em saúde? Avizinha-se a possibilidade de *open data* para dados clínicos (anonimizados, criptografados) para investigação científica e estudos epidemiológicos?

TRANSCRIPT OF THE INTERVIEW TO THE PRESIDENT OF SPMS

Entrevistadora: Autora da tese

Entrevistado: Entrevistado pertencente ao Conselho de Administração dos Serviços Partilhados do ministério da Saúde (SPMS)

Local: entrevista conduzida no gabinete do entrevistado, na sede da SPMS. A entrevista foi conduzida às 9:00H da manhã de dia 12 de Março de 2018, durante cerca de 15 minutos.

Afiliação com o entrevistado: não havia afiliação com o entrevistado

(Início da entrevista)

Entrevistadora: Em que patamar é que o Serviço Nacional de Saúde (SNS) está em termos de serviços de informação e transformação digital?

Entrevistado: *“No Ministério da Saúde, e no SNS em particular, não comparamos mal com o resto da Europa. Pelo contrário, em algumas áreas, nomeadamente na prescrição eletrónica demos um salto muito grande, estando à frente de, praticamente, todos os países da Europa. Ao nível dos hospitais há uma realidade muito heterogénea; há hospitais já bastante bem informatizados, quer públicos quer privados, e há outros que estão mais atrasados, usando ainda muito papel. Depois temos ainda alguns problemas que têm a ver com a vaga de informatização dos anos 90’s e início do século XXI, fazendo com que agora tenhamos sistemas de informação já muito antigos com 20 anos. Esses sistemas estão em fase de substituição, custa muito dinheiro e muito esforço substituir sistemas que estão todos os dias a ser utilizados por praticamente 120 mil trabalhadores. Esse esforço está agora a acontecer e de facto é crítico porque alguns softwares mais antigos não têm a capacidade técnica de dar a informação que é necessária para a gestão de privacidade que o novo regulamento exige [Regulamento Geral sobre a Proteção de 2016/679]. Ou seja, a grande questão não é se o software é compliant ou não; os softwares têm é que ser compliant com as práticas de gestão que as instituições têm que implementar para proteger os dados e a privacidade dos dados”.*

Entrevistadora: E em termos de registo eletrónico de saúde, que é aquilo que do ponto de vista do cidadão mais visibilidade tem, em que ponto se encontra o SNS?

Entrevistado: *“Ao nível da área do cidadão, que é a parte mais visível do registo de saúde eletrónico – o portal – esse sistema é recente, tendo apenas 5 anos. Alguns componentes têm menos tempo do que isso. É um sistema já muito moderno em termos de gestão da privacidade e do acesso, permitindo ao cidadão perceber quem é que acedeu a algumas partes dos seus registos. Agora é importante que não há um só software com todos os dados da saúde; há dezenas de softwares espalhados pelas várias instituições. Um hospital médio, para se ter ideia, tem mais de 30 aplicativos informáticos com dados clínicos. O Hospital de São João, por exemplo, tem mais de 70. Portanto, os dados da saúde das pessoas não estão num só software como estão eventualmente noutros Ministérios, estão sim espalhados em dezenas ou centenas de aplicativos informáticos, em registos de bases de dados diferentes, com questões de interoperabilidade muito rudimentares. Todos os dias há cada vez mais o uso do digital e portanto o cidadão também vai poder ter acesso a perceber onde é que está a sua informação. Porque mesmo o próprio Ministério da Saúde, a própria SPMS, não sabe onde é que está a informação de todas as pessoas.”*

Entrevistadora: Claro, não têm, portanto, essa visibilidade e controlo...

Entrevistado: “Não, nem estatutariamente temos essa competência ou responsabilidade e mesmo que a tivéssemos, não temos ainda a capacidade de fazer isso. Porque, para se entender, em alguns sistemas, há muitos anos atrás, não se faziam registos com número de utente. Portanto, se a pessoa foi registada com nome, e por exemplo as senhoras que mudam de apelido com mais frequência do que os homens, basta que tenham posto uma data de nascimento errada ou um nome que alterou, um sexo que ficou mal registado, que levará a que não se consiga ir buscar aquele pedaço de história e alocar à pessoa. Nós estamos a experimentar agora essa dificuldade no registo oncológico nacional, em que há milhares de registos, alguns regionais, que não vamos conseguir integrar no registo nacional porque, em bom rigor, não conseguimos ter a certeza de que pessoa é aquela informação. Quem registou achou que estava a fazer tudo bem, mas não estava, na verdade, robusto.”

Entrevistadora: Em relação ao registo de saúde eletrónico na vertente destinada ao cidadão – o portal de registo de saúde eletrónico – o que se pode esperar da evolução deste portal?

Entrevistado: “Nós temos muita ideias para o portal, aliás ideias nunca nos faltaram para o portal do cidadão do SNS. O nosso problema é, às vezes, falta de tempo e de recursos para fazer mais rápido as coisas e de alguma forma também percebermos que há um tradeoff entre fazer mais funcionalidades e divulgar as que já existem. Nós temos ainda muitas funcionalidades sub-aproveitadas e é preciso saber rentabilizar o investimento. Por exemplo, o ano passado, em Outubro, disponibilizamos o pagamento de taxas moderadoras que é uma coisa muito utilizada, quer dizer que as pessoas encontraram valor naquilo. Mas o número de novas adesões ao portal ainda não é exponencial, não sobe exponencialmente. Nós temos tido um limite de 1500 a 2000 novos inscritos por dia o que, a este ritmo, demorará quase duas décadas a pôr lá todos os portugueses. Temos que ter noção disso. Há quem diga que se o portal tivesse mais funcionalidades, mais pessoas se inscreviam. Não é muito a noção que nós temos, a noção que nós temos é que devemos ter três ou quatro funcionalidades muito úteis, como por exemplo a marcação de consultas, mas para elas serem muito úteis, o próprio SNS tem que se modificar, tem que aceitar a marcação online, tem que aceitar que em vez de imprimir receitas, vai convidar a pessoa a utilizar o digital. Temos falado muito nisto agora nos últimos meses, na transformação digital do SNS, estando a fazer uma campanha muito forte chamada SNS sem papel porque não serve de nada por muitos serviços no portal se depois aquela informação não é integrada nos processos de atendimento ou de prestação de cuidados. Um outro exemplo é as pessoas irem ao portal registar o peso. Podem fazê-lo. No entanto, se o seu enfermeiro e o seu médico não estão habituados a ir ver o peso online, que podem e conseguem ver mas não estão habituados e quando a pessoa chega à consulta voltam a perguntar, matam todo o esforço que a pessoa teve em utilizar o digital. Portanto, é preciso perceber que as funcionalidades não são apenas funcionalidades do portal; são funcionalidades de uma relação digital que o SNS tem que ter com o cidadão. Isso é muito importante entender-se, mas não é muito fácil. Passa mais por alterar o SNS do que propriamente as linhas de código do portal.”

Entrevistadora: Diria que há um trabalho a ser feito não só da parte dos profissionais para promover a adesão ao portal, mas também da população?

Entrevistado: “Sim. Por exemplo, ainda ontem, através do envio de um email para 80 destinatários do distrito da Guarda, entre elas médicos, enfermeiros, associações e escolas demos início a um projeto a que chamámos Guarda sem papel, que visa envolver as comunidades. Nós temos que introduzir estas pessoas no digital. Elas não vão morrer, nem nós queremos que elas morram sem estarem no digital.

Portanto, não podemos ficar à espera que a sociedade portuguesa se informatize daqui a 20 anos. Daqui a 20 anos já temos que ter este processo acabado. Portanto, temos que pegar nas pessoas mais velhas e ensiná-las a usar o digital. E isso, a saúde sozinha não consegue. Precisa da ajuda das escolas, das associações e das universidades sénior, por exemplo.”

Entrevistadora: Então a estratégia não será esperar pela renovação geracional, mas sim apostar na digitalização dos cidadãos de terceira idade?

Entrevistado: *“Não porque a população portuguesa vai envelhecer muito ainda. Ou seja, no caso de Portugal não se perspectiva uma leva de gente jovem que vá de repente encher o país de adultos dinâmicos e digitais. Será exatamente o contrário: o que nós vamos ter são, daqui a 10 anos, as mesmas pessoas, mas 10 anos mais velhas. As pessoas que têm agora 65 anos, por exemplo, e não usam o digital, daqui a 10 anos estão cá na mesma. E temos que decidir se queremos ter nessa altura essas pessoas de 75 anos a usar o digital e disponibilizar, por exemplo, videochamadas para que interajam com um enfermeiro ou queremos continuar a ter idosos de 75 anos que poderão viver ainda mais 10 anos, com uma prestação de cuidados que podia ser digital e não é. E ao não ser é caríssima, completamente insustentável.”*

Entrevistadora: Em relação a outra das vertentes do portal, a vertente internacional, em que ponto é que estamos.

Entrevistado: *“Neste momento, este ano, vamos lançar os primeiros serviços, com troca de receitas com a Finlândia e a Estónia. Penso que no final do verão já vamos ter os primeiros serviços que farão uso do componente internacional.”*

Entrevistadora: É espectável que o acesso ao registo de saúde eletrónico dos cidadãos se expanda a prestadores não SNS, por exemplo às Farmácias?

Entrevistado: *“Sim, isso já está a acontecer, neste momento as farmácias já registam vacinas, já faz o score da diabetes. Neste momento estamos a olhar para a questão de lhes dar acesso aos dados das alergias.”*

Entrevistadora: Será o regulamento geral de proteção de dados um entrave à partilha de dados em saúde?

Entrevistado: *“Não, eu acho que é bom. Eu acho que nós já estávamos a pensar muito nestes termos, nós já conhecemos o texto do regulamento há três anos e já começámos, não em todos os sistemas, mas naqueles que interagem com o cidadão, a ideia de pedir o consentimento para processar certo tipo de informação. Também a ter muito mais cuidado internamente com a forma como se lida com os dados das pessoas. Eu acho que o regulamento vai ajudar a clarificar também o papel das entidades em relação aos dados das pessoas, o facto de a propriedade dos dados ser do próprio. Não tira de facto responsabilidade nem pode tirar, cada vez há mais risco por isso cada vez terá de haver mais responsabilidade. Vai criar um contexto em que se pode conversar sobre este assunto sem ser uma conversa já gasta de ter de aguardar pela aprovação da Comissão Nacional de Proteção de Dados. A responsabilidade passa a ser das entidades que, ao abrigo de um quadro legislativo exigente, que não se consegue de todo implementar de um dia para o outro, vão ter o seu papel e posteriormente serão auditadas, Eventualmente haverão multas, acredito que a SPMS não vai cumprir tudo o que está escrito na legislação. Mas isso não me tira o sono.”*

Entrevistadora: Já é esperado então que seja uma implementação mais longa e difícil?

Entrevistado: “Eu acho que é uma implementação difícil. A lei portuguesa vai ser alterada, nós ainda não a conhecemos, já contribuimos para o texto mas não conhecemos a versão final. Vai agora para o parlamento, poderá introduzir nuances que podem ser críticas naquilo que é a preparação dos softwares. Se ainda não sabemos nada disso e estamos em Março, é lógico que em maio [quando a legislação entra em vigor] não estará pronto.”

Entrevistadora: É de esperar que cada vez mais hajam dados abertos em saúde? Já temos o portal da transparência, mas e em relação a dados clínicos?

Entrevistado: “O problema aí não é o regulamento porque nós já tínhamos autorização da Comissão Nacional de Proteção de Dados para a produção do RICA – Repositório de Informação Clínica Anonimizada. Nós já temos isso autorizado. O nosso problema é uma questão de tempo, capacidade e financiamento, para além de técnicos qualificados, que não temos os suficientes na área de big data. A nossa barreira na disponibilização para a comunidade académica, e para a comunidade em geral, de mais dados abertos não tem nada a ver com limitações legais. Só tem a ver com limitações financeiras e de recursos humanos, não tem sequer limitações técnicas. São precisos técnicos altamente qualificados para produzir bases de dados de grandes dimensões, bem criptografadas e com bons algoritmos. É preciso também ter um modelo de governação desses dados muito robusto. São coisas que custam muito dinheiro, tempo e skills séniores, e esse é a nossa limitação. A nossa limitação não é neste momento a lei.”

(Fim da entrevista)

APPENDIX B: QUESTIONNAIRE ITEMS

Variável	Items	Reference
Os Portais de Registo de Saúde Eletrónico (RSE) abrangem várias funcionalidades. Numa escala de 1 (nada importante) a 5 (muito importante) indique a importância que considera que cada uma delas tem:	Aceder a informação clínica registada pelo prestador (ex: historial, resultados de testes/exames complementares)	(Pagliari et al., 2007)
	Organizar informação pessoal (ex: agenda, médico(s) assistente(s))	(Pagliari et al., 2007)
	Ser uma ferramenta de suporte na auto-gestão da saúde (ex: planos de cuidados, representação gráfica de sintomas e feedback customizado)	(Pagliari et al., 2007)
	Comunicar diretamente com o prestador (ex: marcação de consultas, renovar prescrições de medicamentos crónicos)	(Pagliari et al., 2007)
	Ter ligações para repositórios de informação em saúde (ex: doenças, sintomas, auto-medicação)	(Pagliari et al., 2007)
	Ter ligações para redes de troca de informação e experiências entre doentes	(Pagliari et al., 2007)
	Integrar informação clínica de outras plataformas	(Pagliari et al., 2007)

Expetativa de desempenho	Usar os portais pode apoiar aspetos críticos da minha saúde	(Tavares & Oliveira, 2016; Venkatesh, Thong, & Xu, 2012)
	Usar os portais pode melhorar a minha eficácia na gestão da minha saúde	(Tavares & Oliveira, 2016; Venkatesh et al., 2012)
	No geral, os portais são úteis na gestão dos meus cuidados de saúde	(Tavares & Oliveira, 2016; Venkatesh et al., 2012)
Hábito	O uso dos portais tornou-se um hábito para mim	(Tavares & Oliveira, 2016; Venkatesh et al., 2012)
	Sou um aficionado dos portais de RSE	(Tavares & Oliveira, 2016; Venkatesh et al., 2012)
	Já não passo sem usar os portais para gestão da minha saúde	(Tavares & Oliveira, 2016; Venkatesh et al., 2012)
Intenção de utilização	Tenciono usar portais de SER	(Tavares & Oliveira, 2016; Venkatesh et al., 2012)
	Tenciono usar portais de RSE nos próximos meses	(Tavares & Oliveira, 2016; Venkatesh et al., 2012)
	Tenciono usar portais de RSE frequentemente	(Tavares & Oliveira, 2016; Venkatesh et al., 2012)
Comportamento enquanto utilizador	Com que frequência utiliza atualmente portais de RSE?	(Tavares & Oliveira, 2016; Venkatesh et al., 2012)
Se já utiliza portais de RSE, indique quais:	"Portal do utente"/ App "MySNS" do Serviço Nacional de Saúde	N/A
	O Meu Portal dos Hospitais/Clínicas Lusíadas®	N/A
	"Portal do Cliente" dos Hospitais/Clínicas da Luz®	N/A
	"MyCUF" dos Hospitais/Clínicas CUF®	N/A
	"MySAMS" dos Hospitais/Clínicas SAMS®	N/A
	Outro(s)	N/A

Note. N/A = Not applicable