Empowering patients in the healthcare process

An analysis about patients' perception of Personal Health Records

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Abstract

Thesis title: Empowering patients in the healthcare process: An analysis about patients' perception of Personal Health Records

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Personal Health Records (PHR) are becoming an important tool for patients to become active participants of their health care and help providers to improve health outcomes and systems performance. However, for PHR to be fully used by individuals it is necessary to understand the value they place on this tool and how can it be designed to improve its usage among patients. Therefore, this study deepens about Portuguese patients' perception of PHR and which are the motivations for healthy and ill individuals to track their personal health status.

A cross-sectional online survey of patients' perception on PHR conducted to Portuguese citizens showed that although there is a lack of awareness of the concept of personal health records and use of online tools to perform health related activities, there is a positive perception about PHR and willingness to start using it in a near future.

Resumo

Título da Tese: Empowering patients in the healthcare process: An analysis about patients' perception of Personal Health Records

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O Registo Clínico Electrónico Pessoal tem vindo a tornar-se numa ferramenta importante para transformar os utentes em participantes activos dos seus cuidados de saúde e ajudar os profissionais de saúde na melhoria de diagnósticos e desempenho dos serviços de saúde. No entanto, para que esta ferramenta seja plenamente utilizada pelos cidadãos é necessário compreender o valor acrescentado que os mesmos identificam no Registo Clínico Electrónico Pessoal e como é que o mesmo deve ser desenhado por forma a incrementar o seu uso por parte dos pacientes. Nesse sentido, este estudo centra-se na percepção dos pacientes portugueses quanto ao Registo Clínico Electrónico Pessoal e quais são as motivações para indivíduos saudáveis ou com alguma doença acompanharem o seu estado de saúde.

Através de um questionário online sobre a percepção dos portugueses quanto ao Registo Clínico Electrónico Pessoal, concluiu-se que, embora haja uma falta de conhecimento deste conceito e uso de ferramentas online para realizar atividades relacionadas com a saúde, há uma percepção positiva sobre o Registo Clínico Electrónico Pessoal e os inquiridos estão dispostos a começar a utilizá-lo num futuro próximo.

Preface – Acknowledgments

Since the beginning of my Master Degree that I knew that writing this final academic project would not be an easy task to complete. As it was not sufficient, I decided to challenge myself by writing it as the same time as I was working on a full-time basis. I do not regret the option I made but I believe that there were some people who certainly helped me to reach this finishing line.

First of all, I would like to thank my friends and family who supported me on both best and worst times and always believed that I would be able to deliver this dissertation on time.

A special thanks to Afonso, who was undoubtedly the person who supported me the most and had the kindness to listen to me countless times during stressful moments. Thank you for being always by my side and making sure I kept a work-life balance during this time.

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As a gesture of gratitude for the love and ambition of providing me the best opportunities to succeed in my life, I would like to dedicate this dissertation to my parents.

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1. Introduction

One of the main strategic priorities for the World Health Organization (WHO) is to strengthen people-centered health systems, giving more empowerment to patients. According to WHO's Health 2020 program, increasing evidence shows that health care becomes more effective if patients are more involved in the whole health care process (World Health Organization Regional Office for Europe 2013). Therefore, engaging people in becoming the co-producers of their own health is a topic that needs to be addressed by national health systems.

Despite of the increasing trend of primary and secondary care professionals to use electronic health records (EHR) - repository of patient data in digital form, stored and exchanged securely -, there is still a lack of focus on providing patient-centered care. Adopting personal health record (PHR) systems for patients and consumers is the right way not only to help patients becoming active participants in their own care but also to help physicians improving health outcomes and health system performance.

Research regarding physicians' perspective on EHR and PHR had been done but few studies have been conducted to evaluate patients' perspectives about how they would like to see information arranged in the PHR portal and what parts of their health care information they would like to have most readily available. As PHR systems are developed mainly for patients' use, it is crucial to understand their preferences and involve them in the design of the systems.

In 2013, *Serviços Partilhados do Ministério da Saúde* (SPMS - a Portuguese National Health Service's (NHS) company) created *Portal do Utente,* an online portal which besides improving the quality and efficiency of care in NHS institutions, gives greater autonomy to patients through the control and management of their health. This innovative platform stands out by its interoperability of systems allowing any health professional to access the PHR of a patient, no matter where one is. This sharing and integration of information ensures that it is constantly updated at any point of contact.

With over one million registered users and approximately five thousand daily visits by health professionals, the *Portal do Utente* is an innovation of SPMS that meets the strategic priorities defined both nationally and internationally. However, the number of users registered and the use of the platform by patients and physicians is still low and in this sense SPMS wants to develop this portal.

Taking into consideration the previous diagnostic, it motivated me to deepen about Portuguese patients' perception of PHR and develop consumer-based strategies in order to facilitate the adoption and use of PHR systems. More than providing additional literature regarding a topic which hasn't been studied in depth yet, these strategies could be applied to *Portal do Utente,* allowing SPMS to achieve part of its strategic goals for 2016 through the increase of citizens registered, use of the platform and update of their health information.

Aligned with this purpose, this dissertation will focus on answering the following research questions:

1. What is the individuals' current perception of PHR?
2. Which are the motivations for healthy and ill individuals to track their personal health status online?

This dissertation is sectioned into five chapters, starting with a brief overview of the context in which the dissertation's topic is inserted. The 2nd chapter will focus on a review of relevant literature regarding electronic health records and personal health records. On the 3rd chapter, it will be explained the methodology used to collect the data in order to answer the research questions. The next two chapters reveal the statistical results of the analysis and its discussion. Lastly, the final chapter will make a brief overview of what has been discussed in this dissertation and give recommendations for PHR providers, such as SPMS, in regard to the design of the platform to increase the attractiveness and, consequently, the number of individuals using PHR.

2. Literature review

2.1 The importance of studying Personal Health Records

A large variety of providers, payers, third-party organizations, including organizations not belonging to the healthcare industry, such as Microsoft, are discussing and developing Personal Health Records systems (Kaelber & Pan 2008). The adoption of these systems not only help patients becoming more engaged on the management of their health but also help health care professionals improving health outcomes and health system performance. According to a cost-benefit model for PHR developed by Kaelber and Pan in 2008, despite of demanding a meaningful investment of billions of dollars for implementing PHR nation-wide, the US healthcare system could save between $13 to $21 billion per year with this tool (Kaelber & Pan 2008).

PHR systems involve high investment and maintenance costs and feature several challenges which need to be addressed in order to succeed in the implementation of these systems. Therefore, is it important to focus on the study of PHR and understand, first of all, the value that patients and health care providers place on the different features of the PHR, how can this tool help providers to deliver better care (Tang et al. 2006) and evaluate the willingness of individuals to adopt PHR and keep it up to date (Wen et al. 2010).

2.2 Electronic Health Records

An electronic health record is defined as a longitudinal electronic record of patient health information generated by at least one health care professional (physicians, nurses, radiologists, pharmacists, laboratory technicians and radiographers) in any care delivery setting (HIMSS 2015). EHR is used in primary care facilities by the staff of general practice, and also in secondary and tertiary care by specialists upon referral by general practice physicians or by teams of specialists in hospitals (Medline Plus 2015).

EHR systems contain different types of components to track patients health record, such as demographics, progress notes, problems, medications, vital signs, past medical history, immunizations, laboratory data, and radiology reports (HIMSS 2015). Depending on the user of the EHR, these components included in the system might differ. As an example, EHR components for nursing staff include additional features related with daily charting (e.g. vital signs and food), which are not available on physicians' EHR (Marr et al. 1993). Although there are several provider of EHR systems, most of them provide EHR that can be time-, problem- and source-oriented, which means that healthcare professionals can access data in chronological order, by problem, and by method by which the information was collected, enabling them to have an integrated view of the patient's health (Häyrinen et al. 2008). Besides having an EHR system, it is important to share health information between organizations in order to achieve a single electronic health record of a patient. Health Information Exchange can create many efficiencies in the delivery and performance of health care (Menachemi & Collum 2011) and it is the next step to the interoperability in health care.

This paperless system that provides access to the health record of a patient and allows health information exchange between health care professionals within a care delivery setting or among different units, brings several benefits not only to patients, but also to health care professionals, organizations and to society in overall. These benefits can be aggregated in three different dimensions: clinical outcomes, organizational outcomes and societal outcomes. In regard to clinical outcomes, these include improvements in the quality of care (i.e. ensuring patient safety, effectiveness, efficiency and timeliness), reduction of medical errors and other improvements in patient level measures (Menachemi & Collum 2011). Concerning organizational outcomes, it takes into consideration increases in financial and operational performance due to, as an example, decrease in billing errors and transcription costs, and increase in communication between caregivers and adherence to specific guidelines (Menachemi & Collum 2011). It also covers the increased satisfaction among patients and clinicians who use EHR. A 2011 nationwide random-digit-dial survey performed in the USA with the goal of determining the relationship between patients experience with a physician who uses a EHR vs. non-user, demonstrated that consumers with physicians who use EHR were more likely to have a better perception about electronic health records and health information exchange and agree they will improve healthcare quality (Ancker et al. 2013). Lastly, by analyzing aggregated medical data, public health organizations are better able to conduct research and improve population health (through monitoring of diseases disruptions and other potential threats) (Kukafka et al. 2007).

However, EHR also comprises some drawbacks which can prevent its adoption by physicians and organizations. Financial issues such as adoption, implementation and ongoing maintenance costs (Menachemi & Collum 2011) and uncertain return on investment (Adler-Milstein & Bates 2010) are some of the key drawbacks highlighted by organizations. Additionally, there is a concern related to the privacy and security of data exchanged electronically between providers (Zurita & Nøhr 2004). Among other drawbacks, one study conducted in different internal medicine clinics demonstrated that EHR adoption contributes to temporary loss of productivity (Wang et al. 2003).

Among several factors that influence the adoption of EHR by doctors, it is important to highlight the age and experience of physicians. According to Cramm (2009), younger doctors tend to have higher adoption rates than the ones with more than 30 years of practice (20% vs 13%). However, one can notice that once they experiment the features of EHR they do not want to use paper-based tools again (Cramm 2009). Additionally, also the size of the hospital/primary care center influences the adoption of EHR systems. In fact, bigger organizations are more likely to use EHR than the smaller ones (adoption rates of 50% vs 9% for practices with less than 4 health care professionals) (Cramm 2009). Furthermore, larger hospitals located in urban areas and teaching hospitals are more willing to have the main features of an EHR than the small, rural or non-teaching hospitals (Adler-Milstein & Bates 2010).

Besides doctors, there are several challenges which need to be addressed when opting to share EHR with patients. According to Beard et al. (2012) there are four types of concerns in regard to this matter: cost and security, problems in assigning responsibilities and rights among the different players, liability issues and tensions between flexible access to data and flexible access to physicians. Urowitz and al. (2008) found that the greatest barrier to adopting EHR is the lack of financial resources. In order to address security issues, new architecture for EHR systems with multiple data-protection features (e.g. authentication processes, encryption) has been developed

(Beard et al. 2012). Regarding responsibilities among different players, it is relevant to decide if patients should have access to their medical information, what and when should it be shown to them, and who owns the custodianship of health information. Recent studies indicate that the majority of patients and doctors agree that patients should be able to access their medical record online and share them with physicians, but they do not agree on the timeliness of the access to the data (Beard et al. 2012). Although flexible access to health data is demanded by patients it is an important issue to understand how much time should doctors spend on engaging in online communication with patients as it may cause a negative impact on the patient-provider relationship if requests are not satisfied (Beard et al. 2012).

2.3 Personal Health Records

According to Markle Foundation, a Personal Health Record is defined as an electronic application through which individuals can access, manage and share their health information with whom they authorize, in a private, secure, and confidential environment (Tang et al. 2006). PHR combine data, knowledge, and software tools, which help patients becoming more active in the management of their own care (Tang et al. 2006). This might provide preventative health care reminders, educational materials and self-management resources (Dontje et al. 2014). Ideally, PHR should include subjective data such as symptom scores, qualitative descriptions of symptoms or medical problems, and responses to questionnaires (Slack & Slack 1972) and also objective data like blood pressure (Tang et al. 2006).

There are three types of PHR: stand-alone, interconnected and tethered systems (Tang et al. 2006). Stand-alone approach is characterized by not being connected to other systems and can be internet-based (e.g. Microsoft HealthVault) or in the form of “smart cards”, USB drives and CDs and it provides more individual control over the access to health data. The reliability of patient-entered data depends on the nature of the information per se, the patient’s general and health literacy and the specific motivations for recording the data (Tang et al. 2006). Interconnected PHR are internet based tools which are integrated with some providers, diagnostic centers or organizations' EHR in some way. Contrary to stand-alone PHR, interconnected systems are usually not free and its pricing is based on connectivity. The main drawback of this approach is the connectivity to agencies which may be complex and expensive (Gee et al. 2015). The last type of PHR is the most advanced one as it allows patients to view their own health information that is stored in their health care provider's EHR and may include additional functionalities, such as schedule appointments, renewal medications and enhance communication between patients and physicians. This PHR is usually free since it is provided by the provider or organizations but it is required that the providers have and use EHR for the tethered approach to work out (Gee et al. 2015). There is a need for improving the interoperability between PHR systems in order to exchange information among health care professionals (Dontje et al. 2014) and provide patients a complete health record of themselves.

This platform provides several benefits for patients regarding the management of their health care. First of all, patients have greater access to credible health information, data and knowledge about their health. Additionally, in many PHR there is an increase in overall communication with health care professionals, either to schedule appointments, request refills and referrals, or to report problems. Last but not least, there are lower chronic disease management, medication and wellness program costs, which are principally important for patients with chronic diseases (Tang et al. 2006).

Although patients are the main beneficiary of PHR, also physicians and hospitals benefit from the implementation of PHR essentially with lower health costs through the decrease in the number of unnecessary visits and calls when patients' doubts can be answered through the platform. However, there is a need to show the impact of PHR on the efficiency of care and other health care costs (Dontje et al. 2014).

The key drawback of PHR systems identified in the literature review is that they are still physician-oriented instead of patient-oriented, so it is more difficult to empower the use and update of the platform by patients (Witry et al. 2010). Additionally, security and privacy is one of the main concerns of PHR users (Ackerman 2010), which should be addressed with, among others, the development of security protocols (Househ et al. 2014).

Regarding patients' adoption of PHR systems, it is less likely that patients who view themselves as fairly healthy to access their PHR. The same happens with elderly individuals and populations with low income which may have trouble to get access to the internet or be uncomfortable or unfamiliar using these systems (Dontje et al. 2014). Furthermore, there are assorted barriers which prevent patients of using PHR. These can be split in environmental, individual-level and educational barriers (Tang et al. 2006). In fact, it is important to motivate individuals to change their perception of PHR in order to make them understand the importance of maintaining and coordinating their own health care information and activities with providers. This can be done through education to patients and, for young individuals, since elementary school. Also it is crucial that purchasers, employers and developers understand the value of PHR and how it should be developed (Tang et al. 2006).

2.4 Consumers' Perception and Behavior

According to Dontje et al. (2014), there is a lack of current perceived value of PHR by patients. This is driven by different factors such as difficulty in accessing the PHR and understanding the information – medical terminology – contained (Dontje et al. 2014), lack of support for using this tool (Kruse et al. 2015) and computer literacy (Tsai & Rosenheck 2012).

In another study conducted by Wen et al. (2010), the perceived importance for accessing PHR electronically by patients depends on their age, internet access, and perceived deficits in information comprehended by health care providers. They concluded that adults aged 65 and over were less likely than younger adults to value the importance of PHR (Wen et al. 2010). However older people were also less prone to use the internet to find health information (Hirth et al. 2007). Additionally, internet users were more likely than non-internet users to understand the importance of PHR and tracking their health information (Wen et al. 2010). Among this group, those who use the internet to track their PHR were more inclined to have completed at least some college courses, meaning that the level of education is important to define the behavior of individuals in regard to PHR use (Wen et al. 2010). Also, perceived deficits in information comprehended by health care providers is pointed out as a predictor of perceived importance for accessing PHR electronically. In fact, users who stated there was a lack of attention by their physicians to ensure they understood and comprehended their health information were more likely to value the access and use of PHR (Wen et al. 2010). Although most part of individuals agree on the importance of PHR to track their personal health information online, the actual use of this tool remains low (Ackerman 2010).

Regarding gender, previous research concluded that women were more disposed than men to search online for health information (Rutten et al. 2006), communicate online with the health care provider (Beckjord et al. 2007) and use online support groups (Fallows 2005).

Concerning the exchange of health information among health care providers, young adults were less likely to value the importance of this issue when compared with individuals aged 35 and above (Wen et al. 2010). Furthermore, previous research found out that the value of health information exchange is influenced by the perceived level of security of their health information managed by providers (Wen et al. 2010). In fact, security and privacy of data is one of the main concerns of individuals when referring to PHR (Kruse et al. 2015). Although most people prefer their health information to be private to a reasonably high degree, making the investment to guarantee that protection is ensured is another matter, when compared to no- or low-cost tools (Lafky & Horan 2008).

Individuals place value on the easiness of access to test results and communication with clinicians (Tang et al. 2006). Additionally, patients recognize that PHR is a useful memory aide and increases their engagement and self-management of their health (Gee et al. 2015). However, the lack of interoperability between providers and health care systems is a frustration for many patients (Gee et al. 2015). They acknowledge that interoperability and health information exchange would be beneficial not only for them but also for health care providers as it provides real-time support (Wen et al. 2010), makes critical medical information available (Luis et al. 2013) and reduces unnecessary testing (Wen et al. 2010), leading to improvements in the quality of care and disease outcomes (Kruse et al. 2015).

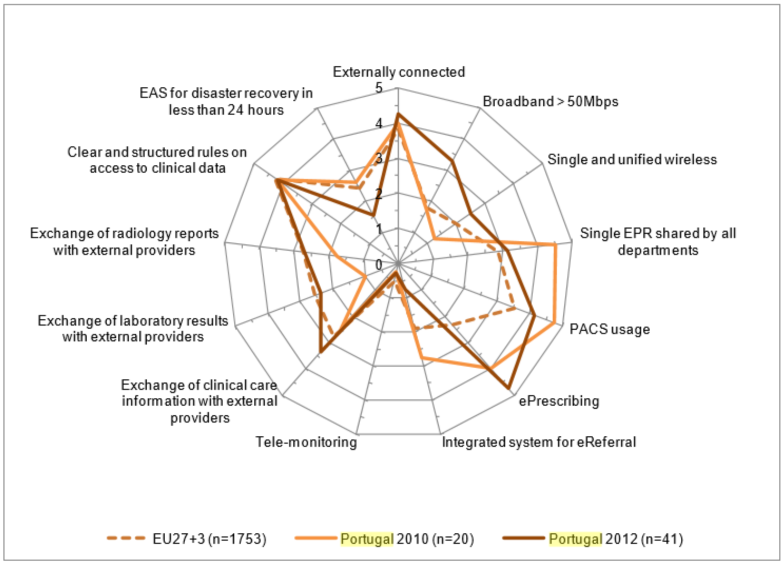
Concerning the features patients would like to view on their PHR include vital signs, weight, height, medication, allergies, exams, organs donation, emergency info and chronic diseases information (Luis et al. 2013). Besides that, a survey targeted to patients with chronic diseases pointed out that being able to communicate with the provider and provider team was the main feature that patients would like to have on a PHR (Gee et al. 2015).

2.5 Portuguese outlook for eHealth

2.5.1 ICT in Portuguese hospitals benchmark

According to a benchmark to the level of eHealth use in hospitals in the European Union done by the European Commission in 2013, Portugal is close to the European average in regard to the eHealth profile. As seen in Figure 1, although the gains are not equally distributed, Portugal is significantly above the average in ePrescribing, broadband speed higher than 50Mbps and PACS usage. It is important to highlight that in terms of exchange of medical data with external providers, Portugal is aligned with the average of the European Union members and above the average concerning the exchange of data among the departments of an organization (Sabes-Figuera 2013).

Figure 1 – Portuguese Acute Hospital eHealth Profile



Note: The scoring scale from 0 to 5 points corresponds to an implementation rate from 0% to 100%.

Source: *European Hospital Survey: Benchmarking Deployment of e-Health Services*, European Commission, 2013

2.5.2 Availability and use of internet in Portugal

According to the *Instituto Nacional de Estatística* 2015 Survey on ICT usage in households and individuals, nearly 70% of the Portuguese households access internet at home (INE 2015). In the last 5 years, the access to the internet increase around 18% among the population aged between 16 and 74 years old. The access to the internet through broadband connection is more frequent among families with children (90%) and those who live in the region of Lisbon (78%). Also the Autonomous Regions of Azores and Madeira account for the regions with highest proportion of households with access to the internet, with 76% and 74% respectively. On the opposite side, Alentejo is the one with the smallest percentage of internet users (61%). However, if it is considered the percentage of people instead of households, both North, Centre and Alentejo account to the regions with least internet users in Portugal (only 64%).

The use of laptop and internet is more common for people up to 44 years old, for men and for those who have completed at least high school. In fact, more than 95% of people whose education is above high school, use the computer and internet. Around two thirds of internet users connect mainly by mobile phone or smartphone. However, more than half of the internet users (54%) limited its use due to security concerns.

It is important to highlight that this survey also concluded that 30% of the Portuguese population still do not use the internet, which is a higher proportion than the European average of 18% (INE 2015).

2.5.3 Social Profiles of internet users

As stated by Espanha et al. (2011), there are four social profiles of internet users in Portugal: “non-relationship with the internet” (33.7%), “customary relationship” (29.2%), “info-exclusion” (21.6%) and “daily relationship” (15.5%). The first social profile covers people who have internet at home but do not use it or need help by a third party to use it and is composed by individuals aged between 45 and 64, with low levels of education and income between 501€ and 1000€. The “customary relationship” profile covers individuals who access the internet 2 to 3 times per week. This group consists of people aged between 25 and 44 who have completed the mandatory level of education and with a household income ranging between 1001 and 1500€. Additionally, there is the “info-exclusion” social profile which, as the name suggests, includes individuals who do not access to the internet nor knows how to use it. Usually primary sector’ workers and older people who did not attend school and have the lowest income are the ones that belong to this group. Last but not least, there is the group of individuals who have a daily relationship with the internet and it is composed by the population belonging to the highest social classes, with the highest income and education levels, but also by the young adults and students (Espanha et al. 2011).

3 Methodology

3.1 Research Questions

This dissertation focus on answering to two different research questions:

RQ1: What is the individuals' current perception of PHR?

RQ2: Which are the motivations for healthy and ill individuals to track their personal health status online?

For Research Question 2, the following eight hypotheses were developed with the aim of understanding the motivations of individuals:

H1 Individuals with chronic diseases are more willing to use PHR than the healthy ones.

H2 Individuals who perceive their health status as fair or poor are more motivated to use PHR when compared with the ones who acknowledge their health status as good or excellent.

H3 The level of comprehension of information provided by doctors influences the willingness to use PHR.

H4 Patients whose health care provider uses laptop or tablet to access their medical record are more willing to use PHR.

H5 Accessing test results online is considered as a significant motivator to use PHR.

H6 Being able to communicate with doctors online is considered as a significant motivator to use PHR.

H7 Individuals with higher education level are more motivated to use PHR tools than the ones in a lower level.

H8 Women are more likely to use PHR than men.

3.2 Type of Methodology

In order to answer to the previous questions, both primary and secondary data was collected. First of all, and as described in the previous section, a literature review was developed to deepen the knowledge about EHR, PHR, consumer perception and behavior towards PHR and the Portuguese outlook for eHealth. After analyzing this secondary data, primary and quantitative data was collected through the distribution of surveys to the Portuguese population to understand their perception about PHR.

3.3 Survey Context

A cross-sectional online survey of patients' perception on PHR was conducted during 3rd-28th November to all Portuguese citizens. The goal of this survey was to, besides understanding the patients' current perception on PHR, identify the motivations for healthy and ill individuals to track their personal health status, analyze their preferences regarding PHR and check if there was any significant difference between individuals with any chronic disease and the healthy ones.

3.4 Survey Development

The literature review on EHR, patients' perception and use of PHR and the Portuguese online PHR developed by SPMS helped to identify the key issues to include in the survey. Additionally, in one of the papers analyzed there was a cross-sectional telephone survey of consumer attitudes towards PHR conducted in 2009 in the greater Buffalo region of New York State (Patel et al. 2011) which covered almost all the relevant topics I would like to address. Therefore, I adapted it and used it in my study. Additionally, other questions were added and the value added of the SPMS' Board of Information Systems was important to help understand who should be the target and how to contact them.

The survey included some types of variables related to: health status and satisfaction, internet experience, preferences regarding PHR, perceptions towards the potential use and management of PHR, and sociodemographic characteristics (for consultation of the survey design please see Appendix 1).

In order to ensure consumers understood what was a PHR, the survey described it, according to the Markle Foundation, as “an electronic application through which individuals can access, manage and share their health information, and that of others for whom they are authorized, in a private, secure, and confidential environment” (Tang et al. 2006).

Then, a few questions were asked to understand how people perceive their health status, how often did they go to a health care institution (either primary, secondary care or other) and, in overall, how satisfied they are with the service. To access internet experience, it was asked how often they use the internet either for health or other purposes. The major part of the survey included questions related to patients’ perception and attitudes regarding PHR such as their willingness to access, use and update their PHR, which types of information should be included, which activities they would like to conduct using a PHR and if they have already done it online, potential benefits of this application for the end-user and to whom would they give authorization to access their medical data. Last but not least, few questions in regard to *Portal do Utente* were asked to figure out the awareness of this PHR by citizens and collect their feedback if they were already users

In order to ensure the survey was comprehensible, a pre-test was done to a small sample of 5 people and a few changes were done before making it available online.

3.5 Survey Distribution and Analysis

The distribution of this survey was made online by a range of Portuguese Associations that support individuals with chronic diseases (for a list of associations which shared the survey please see Appendix 2) and also with my professional and personal network.

Over this period 329 answers to the survey were collected, but only 256 were considered for analysis’ purpose, as the remaining ones did not reach the end of the questionnaire. Additionally, as the number of respondents living in Madeira and Azores was too small, the analysis of results was focused on mainland Portugal and, therefore, two answers were erased. Last but not least, the responses of individuals aged less than 18 years old were also deleted because they were underage and in general they still have a caretaker, so they were not so concerned about their health. Concluding, the final number of answers considered was 252.

In order to characterize the sample, descriptive statistics concerning demographics, health status and interaction with health care providers, and internet habits were performed. In second place, to answer to RQ1, a myriad of descriptive statistics was developed to analyze the following topics: Awareness of the concept and Willingness to use PHR, Potential effects of PHR, Features, Health care related activities done online and authorization to access PHR. In addition, the awareness of *Portal do Utente* was evaluated as well as its use by registered users and willingness to register of the individuals who were not aware of this portal. All the analysis and graphs included in this dissertation were made on Excel 2013 software.

In terms of RQ2, eight different Chi-squared tests were performed and a confidence interval of 95% was chosen. Therefore, the null hypotheses were rejected if the p-value was lower than 0.05. The variable chosen to represent the motivation of people to track their PHR was Willingness (in the survey it corresponds to the answers to the question: “Please indicate how strongly you agree or disagree with the following statement: I am interested in using a personal health record on the Internet to view my health information and manage my healthcare”). The values of this variable could range between 1 and 5 (Strongly Agree to Strongly Disagree) and, since some of these values were less frequent responses, a small adjustment was made in order to ensure that the output of the test was correct (data was aggregated and the variable could have a value of 1 –Agree- , 2 –Neutral- or 3 –Disagree). Additionally, for H4 a new variable for the laptop use by physicians was created in which the observations of respondents who did not know if doctors use this technology were erased. These Chi-squared tests were done by using R software.

4 Results

This section is divided in two different subsections: first it will be used descriptive statistics to characterize the overall sample and its perception about Personal Health Records. After this analysis, the results of the eight different Chi-squared tests defined for RQ2 will be showed.

4.1 Descriptive Statistics

4.1.1 Demographics

The demographic variables studied in this sample were age, gender, residence, education and income (Appendix 3). In terms of gender, the survey was answered by 168 women and 84 men, showing that there is a predominance of female (67%) over male respondents (33%).

Regarding age, there is a lack of responses of elderly people mainly because this survey was conducted online. Although there were created 7 different age groups, one can summarize that 40% of the respondents were aged between 18 and 24 years old, 31% were adults between 25-44 years old, 24% aged between 45-64 years old and 5% with more than 65 years old.

In terms of residence, 62% of the people surveyed live in the Lisbon Metropolitan Area, 20% in the Centre, 15% in the North and the remainder in Alentejo and Algarve. In fact, there is a limitation to the analysis as there is significant discrepancy between respondents who live in Lisbon Metropolitan Area and the remaining NUTS II (Nomenclature of Territorial Units for Statistics).

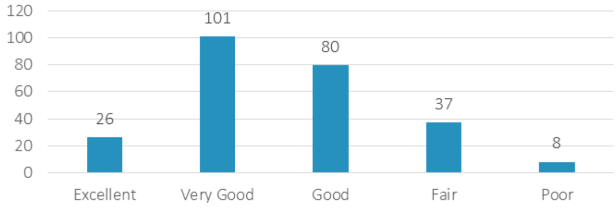
In regard to education, 80% of the respondents had superior education (40% had a Bachelor Degree, 21% were Postgraduate, 9% a Master Degree and 4% a PhD or more) contrasting with 20% who were High School graduates. None of the individuals had only the elementary school level. Although this survey included either active and inactive population, one can conclude that in terms of education it is not representative of the Portuguese population since only 25% of the active population has superior education (INE 2014b).

Concerning the average monthly net wage, 30% answered it was below 500€, 28% between 501€ and 1,000€, 33% between 1,001€ and 2,000€, 9% between 2,001€ and 4,000€ and 1% higher than 4,001€.

4.1.2 Health Status and interaction with health care providers

Among the 252 answers collected, 10% of the respondents perceive their health status as excellent, 40% as very good, 32% as good, 15% as fair and only 3% believe their health is poor.

Figure 2 - Perceived Health Status

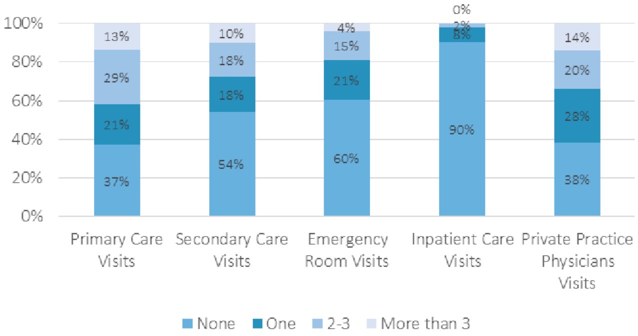


Source: Own analysis

Regarding chronic diseases, 72 out of 252 stated to have at least one chronic disease (Appendix 4). Multiple sclerosis, diabetes, cancer, rhinitis and sinusitis are examples of chronic diseases identified in this sample.

Regarding the number of visits to health care units in 2014, more than 50% of the respondents did not go to a secondary care center, Emergency Room or was submitted to inpatient care. For each type of health care facility, less than 14% of the respondents made more than 3 visits in the last year. However, 63% of them did at least one visit to a primary care facility and 62% to a private practice unit.

Figure 3 - Number of visits to health care units in the last year



Source: Own analysis

Each time a person goes to a doctor appointment, there might be some issues in what concerns to the comprehension of the information provided by the doctor. Only 7% of the respondents stated they have frequent troubles comprehending the information or not understand it at all, whereas 21% have this problem sometimes and 72% occasionally or not at all (Appendix 4). The main reason for having some kind of issue understanding their doctors' diagnosis and treatment is related with complex medical terms. Overall, 75% of the respondents were satisfied or very satisfied with the quality of the health care service, contrasting with 12% who were indifferent and 14% who were dissatisfied or very dissatisfied (Appendix 4).

In terms of taking decisions concerning their health, 58% of the individuals said that it is taken together with the doctor as a team, 31% trust on the physician for being him taking the decision and 10% stated that it is them who take the decision concerning their health care (1% did not choose any of these) (Appendix 4).

4.1.3 Internet Habits

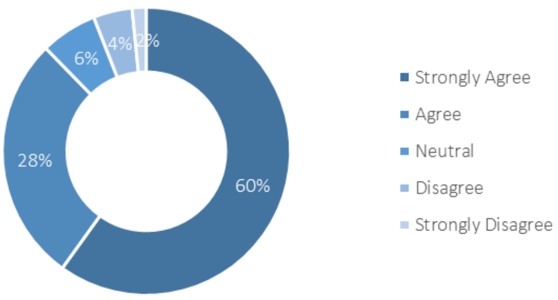
This sample is characterized of heavy users of the internet, with 95% of the respondents affirming that they access the internet may times per day and 4% to use once a day (Appendix 5). When questioned about the usage of laptop or tablet by their physicians, 80% confirmed that they use it to access their medical record, 4% denied it and 16% did not know if they use it (Appendix 5).

4.1.4 Perception of PHR

4.1.4.1 Awareness of the concept and Willingness to use PHR

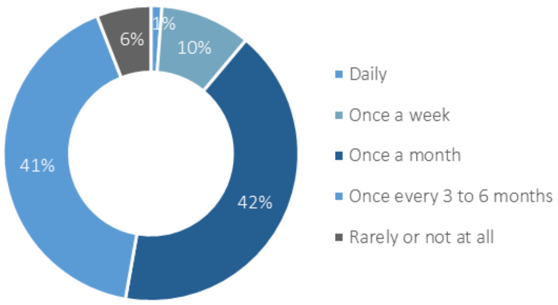
When faced with the concept of Personal Health Record, 128 respondents (51%) affirmed to already know the concept, in contrast to 124 (49%) who were not aware of this definition (Appendix 6). Although a significant part did not know the concept, 60% of the respondents strongly agreed and 28% agreed with the sentence "I am interested in using a PHR on the Internet

Figure 4 - Agreement with the sentence: "I am interested in using a PHR tool"



Source: Own analysis

Figure 5 - Frequency of Access



Source: Own analysis

to access my health information (e.g. medical record) and manage my healthcare". Only 6% of the sample disagreed with the sentence and other 6% were neutral.

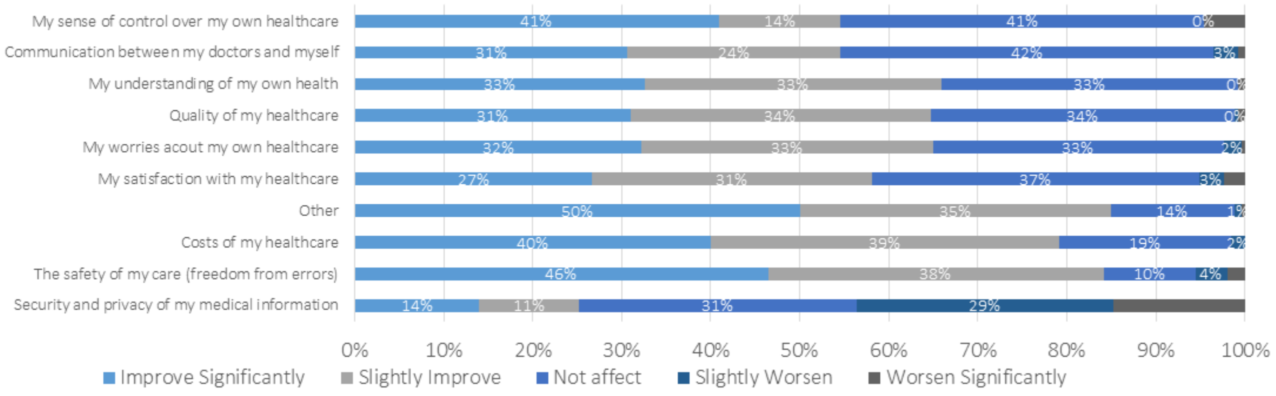
When asked how often they would access their PHR, just 6% of the people surveyed said they would rarely use the PHR. 42% estimated they would access it once a month, 41% once every 3 to 6 months, 10% once a week and 1% in a daily basis.

In terms of ease of use of this tool, 39% of the respondents perceive it will be very easy, 52% easy and the remaining 10% to be difficult (8% slightly difficult and 2% difficult) (Appendix 6).

4.1.4.2 Potential effects of PHR

In order to understand the perception of patients on PHR, an evaluation of their opinion in regard to the potential effects of this tool is needed (Appendix 7). In general, and as seen in the figure below, almost all the options listed would increase or not be affected with the use of a PHR. Pointing out the most impactful issues, 84% of the answers acknowledge that the probability of diagnosis being free of errors will be increased with the access to PHR by physicians, which will, consequently, increase the safety of their care. Additionally, 79% agree that it will improve the costs of their healthcare, which means, it will decrease the spending on health. Examples of potential effects mentioned in "Other" include reducing waiting time in health care facilities and communication between medical departments.

Figure 6 - Potential Effects of PHR



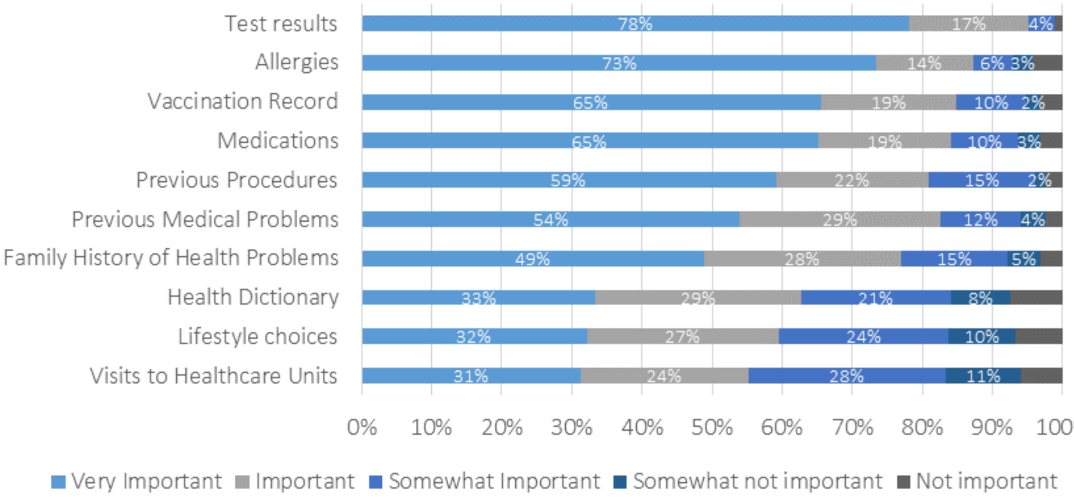
Source: Own analysis

However, 44% of the respondents recognize that the security and privacy of their medical information will become poorer by putting it online in this new tool.

4.1.4.3 Features

When asked about the importance of a list of features to be included in the PHR, the respondents identified test results (78% of the answers), allergies (73%), vaccinations record (65%), medications (65%), previous health procedures (59%) and medical problems (54%) as very important to be included in this tool. Description of previous appointments/visits to healthcare units, lifestyle choices and health dictionary are among the features with less importance for patients to be available in a PHR. In fact, 17% of the respondents agreed that visits to healthcare units were somewhat or not important at all and 16% stated that lifestyle choices and the development of a health dictionary were not important. All the remaining features were important in some way for more than 90% of the people surveyed.

Figure 7 - Features' importance on a PHR

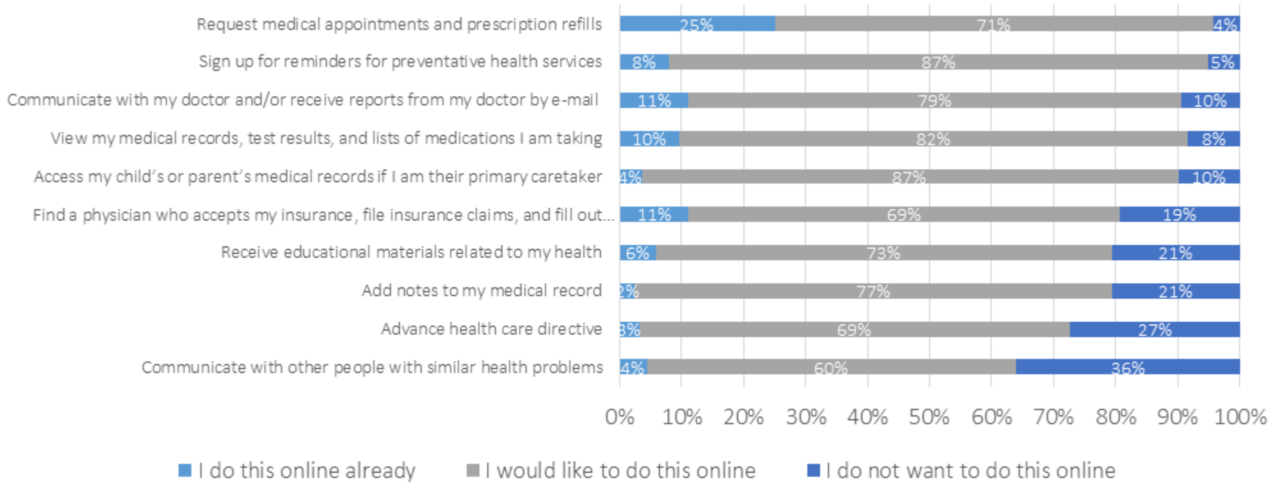


Source: Own analysis

4.1.4.4 Health care related activities done online

Regarding consumers' preferences for health care activities performed online, nowadays few of the respondents use the internet for these purposes but were willing to do so. In fact, more than 90% already use or would like to perform more activities online such as: request medical appointments and prescription refills, sign up for reminders for preventative health services, communicate with their doctors and/or receive reports from them by e-mail and access to their children's or parents' medical record if they are their primary caretaker (Appendix 8). Request medical appointments and prescription refills was the action with the highest proportion of people doing it online nowadays (25% of the respondents).

Figure 8 - Preferences for health care related activities done online

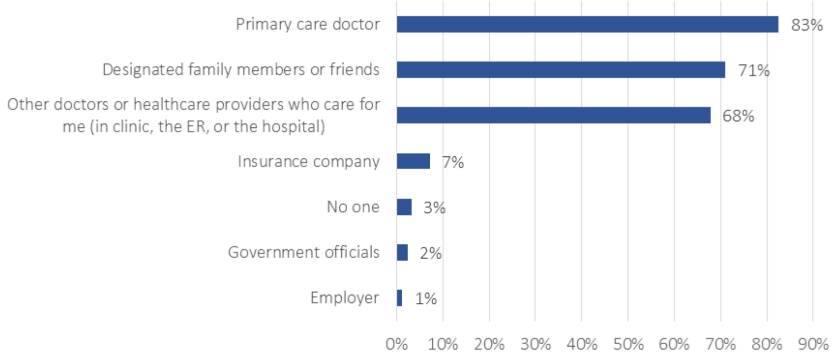


Source: Own analysis

Communicate with other people with similar health problems through support groups or forums or create an advance health care directive are among the activities which patients prefer not to do online. In fact, 36% of the individuals surveyed do not want to use forums for health purposes and 27% prefer to write their advance health care directive in person (Appendix 8).

4.1.4.5 Authorization to access PHR

Figure 9 - Authorization to access PHR by a third party



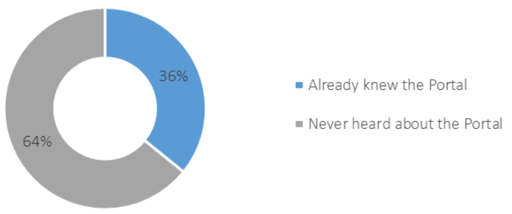
Source: Own analysis

In the survey, it was asked to whom the respondents would give authorization to access their PHR, and each of them could choose more than one answer. Primary care doctor was the main third party selected with 83% of the respondents choosing him to give access to their PHR. Additionally, the majority selected that designated family members or friends (71%) and other doctors or health care organizations which they visit (68%) should also have access to their health record. It is important to mention that 3% of the respondents affirmed they would not want anyone to have access to their PHR.

4.1.5 Awareness and usage of *Portal do Utente*

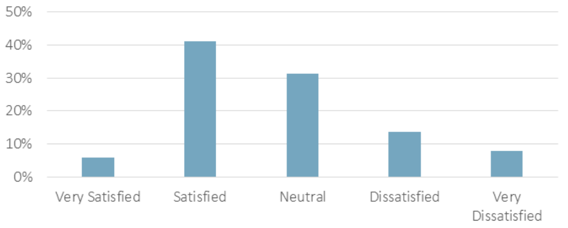
One of the objectives of this questionnaire was also to determine individuals' awareness and opinion about one of the portals of *Plataforma de Dados da Saúde* developed by SPMS, the *Portal do Utente*. In fact, out of 252 answers only 91 (36%) already knew *Portal do Utente* and 52 of them (57% of the individuals who knew *Portal do Utente*) were registered in the portal. However, just 31 individuals (60%) were active users of the platform, which leads to the conclusion that only 12% of the total number of respondents were users of *Portal do Utente*. Among the 161 individuals registered, the majority were very satisfied (6%), satisfied (41%) or neutral (31%) with the service provided by the portal. However, 14% of them were dissatisfied with the performance and 8% very dissatisfied.

Figure 10 - Awareness of Portal do Utente



Source: Own analysis

Figure 11 - Satisfaction of registered users



Source: Own analysis

Among the 161 individuals who were not aware of this tool, 128 (80%) were willing to register in the platform after being presented to them what this tool is and which features does it have.

4.2 Hypothesis Testing

According to the Chi-Squared tests performed, four out of the eight hypotheses formulated were considered as valid. Below there is a summary table of the findings for Research Question 2:

Table 1 - Hypothesis Testing Results		
H1	Individuals with chronic diseases are more willing to use PHR than the healthy ones	Not valid
H2	Individuals who perceive their health status as fair or poor are more motivated to use PHR when compared with the ones who acknowledge their health status as good or excellent.	Not valid
H3	The level of comprehension of information provided by doctors influences the willingness to use PHR.	Valid
H4	Patients whose health care provider uses laptop or tablet to access their medical record are more willing to use PHR.	Valid
H5	Accessing test results online is considered as a significant motivator to use PHR.	Valid
H6	Being able to communicate with doctors online is considered as a significant motivator to use PHR.	Valid
H7	Individuals with higher education level are more motivated to use PHR tools than the ones in a lower level	Not valid
H8	Women are more likely to use PHR than men.	Not valid

H1 Individuals with chronic diseases are more willing to use PHR than the healthy ones.

H0: Willingness and Chronic Disease variables are independent from each other.

Ha: Willingness and Chronic Disease variables are not independent.

After computing this test, the X-squared = 0.7165 and the p-value = 0.6989, so one does not reject the null hypothesis. This means that there is no significant difference between individuals with chronic diseases and healthy ones in regard to the willingness to use PHR.

H2 Individuals who perceive their health status as fair or poor are more motivated to use PHR when compared with the ones who acknowledge their health status as good or excellent.

H0: Willingness and Health Status variables are independent from each other.

Ha: Willingness and Health Status variables are not independent.

The Chi-squared test resulted in an X-squared = 13.9757 and the p-value = 0.0824, so once again one does not reject the null hypothesis, meaning that the willingness of an individual to use PHR does not depend on their health status.

H3 The level of comprehension of information provided by doctors influences the willingness to use PHR.

H0: Willingness and Comprehension variables are independent from each other.

Ha: Willingness and Comprehension variables are not independent.

The output of this test was an X-squared = 20.2876 and a p-value = 0,009301, so the null hypothesis is rejected. This indicates that the willingness of an individual to use a PHR varies with their understanding of the information provided by the doctor during appointments, tests, or any other form of interaction. There is a positive correlation of 0,043 between these two variables which leads to the conclusion that people who have more troubles comprehending their physicians' information are more willing to use PHR.

H4 Patients whose health care provider uses a laptop or tablet to access their medical record are more willing to use PHR.

H0: Willingness and Laptop Use by Physician variables are independent from each other.

Ha: Willingness and Laptop Use by Physician variables are not independent.

After computing this test, the X-squared = 9.8493 and the p-value = 0.007265, therefore the null hypothesis is rejected. In fact, there is a positive correlation of 0.21 between these two variables which means that patients whose doctor uses a laptop or tablet to access their medical record are more prone to use the PHR.

H5 Accessing test results online is considered as a significant motivator to use PHR.

H0: Willingness and Accessing test results online variables are independent from each other.

Ha: Willingness and Accessing test results online variables are not independent.

The output of this test was an X-squared = 136.0147 and a p-value < 2.2e-16 so one does reject the null hypothesis of the variables being independent. There is a strong positive correlation of 0.5541 which means that individuals who already use the internet to access their test results or which to do it online, are more motivated to use the PHR than individuals who still prefer to access this in paper.

H6 Being able to communicate with doctors online is considered as a significant motivator to use PHR.

H0: Willingness and Communicating online with doctors variables are independent from each other.

Ha: Willingness and Communicating online with doctors variables are not independent.

The output of this test was an X-squared = 20.3966 and a p-value < 0.00041 so one does reject the null hypothesis of the variables being independent. There is a positive correlation of 0.1136 but not so strong as in the previous hypothesis tested. This correlation means indicate that individuals who already communicate or wish to communicate online with their health care providers are more willing to use the PHR than the ones who still prefer to do it by phone or in person.

H7 Individuals with higher education level are more motivated to use PHR tools than the ones in a lower level.

H0: Willingness and Education variables are independent from each other.

Ha: Willingness and Education variables are not independent.

The results of this test involve an X-squared = 9.13 and a p-value = 0.3314, so one does not reject the null hypothesis. Concluding, one cannot admit that the level of education of an individual has influence on their willingness to use PHR.

H8 Women are more likely to use PHR than men.

H0: Willingness and Gender variables are independent from each other.

Ha: Willingness and Gender variables are not independent.

The output of this Chi-squared test is an X-squared = 5.3538 and a p-value = 0.06877, so once again the null hypothesis is not rejected. Therefore, and according to this sample, one cannot state that the gender of a person influences their motivation to use PHR.

5 Discussion

In this chapter, the results obtained from the questionnaire and how do they relate with the published literature mentioned in the literature review will be discussed for each research question.

5.1 What is the individuals' current perception of PHR?

Regarding the concept of Personal Health Records, it was surprising that almost half of the respondents were not aware of this concept. However, this proportion may not be completely correct because there is a chance that individuals already knew this concept but not in this way. For instance, 32% of the respondents who knew *Portal do Utente* affirmed that they did not know the concept of PHR. Yet, this portal is an example of personal health record but respondents were not aware of it. Even though there was a large fraction of people who did not know the concept of PHR, 88% agreed they would be interested in using this tool to access their health information and manage their healthcare. In terms of frequency of utilization, the majority estimated they would access it once a month or every 3 to 6 months. However, this might not be so reliable for individuals who have never used this tool so it would be only an estimate in people's minds and not a measure of willingness to use PHR. In regard to the ease of use of this tool the vast majority believe it would be easy to manage which might be related to the computer literacy and internet use of respondents. As this sample is mainly composed by active internet users (95% admit to access it many times per day), it is possible they have enough computer literacy to know how to use different types of software. Therefore, one might conclude that if in this sample there were answers of non-users of the internet and of the ones who live in regions where internet penetration is lower, perhaps the perceived ease of use would not be so clear.

Perception of PHR can be measured by the perceived effects that it might provoke in terms of security, cost, quality of healthcare, self-management, among others. According to Kruse et al. (2015), security and privacy of data is one of the main concerns of individuals in relation to PHR. Indeed, 44% of the respondents said that PHR usage would slightly or significantly worsen the security and privacy of their medical information. On the other hand, the individuals surveyed pointed out many positive effects that PHR would provide. First of all, patients believe that the safety of their care will be improved by making their full medical information available to physicians. In the literature review, also Kruse et al. (2015) found out that patients believe PHR will bring benefits not only to themselves but also to health care providers in terms of better disease outcomes. In second place, PHR can reduce unnecessary testing and medical appointments due to the storage of patients' medical record and tests results on a single platform. Also communication with doctors through the PHR would decrease the number of unnecessary appointments. All these will lead to a decrease in costs for both patients and providers. Lastly, it is important to mention that patients have the perception that, in a matter of fact, PHR were developed to improve the understanding of their health and reduce their worries.

Moving to, perhaps, one of the most important topics, patients affirm that it would be very important to include test results, allergies and medication history, vaccination record, and previous heath procedures and medical problems in their PHR. Although more than 80% of the respondents perceived health dictionary, lifestyle choices and visits to healthcare units as some kind of important, these feature were among the top 3 with more individuals stating it would not matter. Surprisingly, and particularly relating to previous thoughts where it was believed that health literacy should be improved in order to facilitate their comprehension when analyzing results or talking with doctors, patients do not place value on having a health dictionary available on their PHR. Therefore, a different approach to increase health literacy needs to be developed.

In regard to health related activities performed online, one might conclude that despite the increasing internet and new technologies usage today, few Portuguese people carry out these type of activities online (less than 25% of the internet users). Nevertheless, most part of them wish to do it in a nearer future and it is only a minority who still prefer to perform this in person. Request medical appointments and prescription refills is the most preferred activity and also the one with more individuals already doing it online. Additionally, and in accordance with the main goal of PHR development, people want to become better managers of their health. It is showed by the fact that 87% of the respondents would like to sign up for reminders for preventative health services (such as blood analysis and vaccination requirements) and 77% would value it more if it would be possible to add notes to their medical record. The quite high percentage of individuals preferring to write their advance health care directive in paper might be related to the sensitivity of this topic.

Lastly, in terms of authorization, individuals tend to give authorization to the ones who might be directed related with them. Primary care and other doctors who are responsible for their health and also designated family members or friends are the main options for people that might access their PHR. This shows that PHR is perceived not only as a tool to help patients becoming active in the management of their own care but also as a way to improve others' work and knowledge about their health as a whole. This might be very helpful in a case of emergency in which the emergency contact (a designated family member or friend) is aware of the health record of the person in charge and may provide better indications to doctors.

In the Portuguese specific case, it is a matter of fact that *Portal do Utente*, which was launced in 2012, is still unknown for the majority of people and the usage of this platform is still low. Furthermore, the use of this online tool developed by the Health Ministry may not be related with its main purpose of becoming more engaged on their health. In fact, there is a significant probability that citizens use it as an administrative tool to essentially schedule appointments (which is easier and faster than by phone or in person) and ask for exemption of participation fees. In spite of being a useful tool which is still undervalued by patients, perhaps *Portal do Utente* needs to be restructured in order to guarantee the maximization of the use of all its features.

5.2 Which are the motivations for healthy and ill individuals to track their personal health status online?

Although the aim of PHR was for individuals to become more engaged on managing their health (Tang et al. 2006), nowadays there is still few Portuguese citizens who know this concept and, as a matter of fact, use this tool. As an example, not many individuals knew *Portal do Utente*, the online portal developed by a Portuguese NHS's company, and only 12% of the respondents were users of this PHR. This is in accordance with Ackerman (2010), who stated that the actual use of this tool remains low among patients. Therefore, it is important to understand what makes individuals want to use PHR so that this tool can be adapted to their motivations and promote it in an effective manner to individuals.

Contrarily to the expectations, a significant difference between individuals with and without chronic diseases in regard to the willingness to use PHR was not found. Plus, the perceived health status was not considered as a motivator for individuals to track their health record. Therefore, the use of PHR is independent of the health status and diseases that an individual might have. Although Dontje et al. (2014) concluded that people who view themselves as fairly healthy are less likely to access their PHR, another perspective is in accordance with the findings of this dissertation. In fact, a previous survey conducted to US citizens in 2007 also found that general health status was not associated with PHR use (Wen et al. 2010). This might be related with the fact that people are becoming more aware of the importance of preventative healthcare and they want to be informed about their health regardless of their health status. Related to this, is the impact of comprehension of information provided by doctors to patients. In fact, and according to the results, people who have more troubles understanding their health information are keener to use PHR than patients who comprehend the information communicated by their doctors. A possible reason for this is that if an individual does not understand all the information in the doctor's office, the probability of memorizing it and try to understand it later might be diminished. Hence, individuals may find PHR as a solution to gather all their health records, turning it possible to try to understand this information later, perhaps with the help of an online search engine or another person.

Laptop or tablet use by doctors to access patients' health record is also considered as a motivator for individuals to use PHR. In fact, the computerization of medical activities in Portuguese hospitals had shown an upward trend during the last ten years, with 83% of the hospitals using electronic health records in 2014 (INE 2014a). This trend might also be reflected in private practice and primary care centers, which will affect patients. They might start realizing the benefits of access and store their medical data online by initiative of the doctor or by requirement. In the former case, it consists of health care providers making test results available online instead of paper. This way, patients are obliged to use a laptop with connection to the internet to be able to access their results.

Accessing test results and being able to communicate with doctors online were considered as significant motivators to use PHR. According to the results, 10% of the sample already view their medical records, test results, and/or lists of medication they are taking online and 82% would like to start doing this. The positive correlation found means that the willingness of people to access these features online is related with the willingness to use PHR. Therefore, one might conclude that accessing this information online is considered as a motivator to use PHR. In terms of communication, although contact by e-mail is a common issue nowadays, the same is not demonstrated when talking about communicating with doctors. Out of 252 respondents, only 11 were already talking with their physicians online, but 150 would like to start doing this. With the increase in difficulty for many individuals to guarantee a work-life balance, perhaps they would like to use a PHR to communicate with their doctors instead of calling or scheduling an appointment with them. It is a fast and easy way to clarify health issues a person might have or get an opinion about test results without obliging the two parties to be available at the same time. However, an importance issue arises with this topic which is the additional amount of time doctors would need to spend on online communication (Beard et al. 2012). Therefore, this feature might be one of the most difficult to implement without compromising the patient-provider relationship and the quality of the health care (doctors may not pay much attention reading and answering e-mails as needed).

Concerning demographics, education and gender these were the indicators chosen that possibly could be motivators to use PHR systems. Although Wen et al. (2010) stated that individuals with superior education would be more inclined to use PHR, it was not seen with this sample. Perhaps it is related with the limitation of diversity in the level of education of this sample, since 80% of the respondents had some kind of superior education. The lack of responses of people with lower education could have affected the results of this Chi-squared test. Regarding gender, although in previous studies it was concluded that women were more likely than men to search online for health information (Rutten et al. 2006) and communicate online with their health care provider (Beckjord et al. 2007), it was found that women were as likely as men to use PHR to track their health.

6 Conclusion

Personal Health Record is a tool designed with the aim of making patients more active in the management of their health. It has innumerous benefits for both patients and providers and it is seen as a strategic priority for WHO as it strengthens people-centered health systems. As a matter of fact, national health systems need to start addressing this issue and, implementing PHR solutions may be the answer.

In Portugal, the concept of PHR is still uncommon for almost half of the individuals surveyed. However, when faced with this concept, individuals change their minds and there is a significant part who is willing to use PHR to access their medical data and manage their health. They perceive it as a tool with many positive effects and despite the fact that the privacy and security of their medical data is threatened, the cost-benefit of using PHR is still positive. In fact, it was few the number of individuals who stated they would not want to give access of their PHR to anyone. Therefore, individuals perceive PHR as a useful tool not only for them but also for the ones who are responsible for their health in the sense it might help the former to develop better diagnosis, free of errors and with less costs for the patient.

Although nearly 70% of the Portuguese households access internet at home (INE 2015), there is still a lack of conversion of individuals who use the internet for health related purposes. Nevertheless, they would like to start performing some tasks online (mainly request medical appointments and prescription refills and sign up for reminders for preventative health services) if they have the opportunity to do so. This shows that Portuguese people see some online activities as motivators to use PHR and would like to start having a preventative approach rather than a reactive one concerning their health. Therefore, PHR systems should be adapted to include features which enable individuals to satisfy their individual and family healthcare needs. Furthermore, it needs to be promoted as a tool designed by patients and for patients with the aim of simplifying the comprehension of their health and improve the management of their care. However, it is important to take into consideration the lack of computer literacy that is present in a significant portion of the Portuguese population. In fact, it is considered a critical barrier for PHR adoption which is more difficult to address, especially to the elderly ones. One possible solution is to develop counter-desks in primary care centers which would help users to access their PHR, update their medical data and share health information with the third-parties they choose.

In this study it was also found that the lack of comprehension of information provided by doctors was a motivator to use PHR. Therefore, it is important to improve health literacy among individual so that it is easier for them to understand procedures and diagnosis. For the younger people, it should be considered the idea of implementing workshops to teach children about the importance of Personal Health Records, how this tool works and what is the importance of taking an active role in the management of their health care. For adults, creating a health dictionary which would be available on a PHR seems an interesting way of improving health literacy. However, it is important to also take into account the individuals who were not interested on having a health dictionary in their PHR. As a way to improve their health literacy, doctors should become teachers of patients, making a bigger effort to explain the medical terminologies used and encourage their patients to use PHR.

In regard to *Portal do Utente,* there is a lack of awareness of this tool among the Portuguese citizens surveyed. Additionally, the overall satisfaction of current users is not homogeneous what leads to the conclusion that there is still work to be done to improve the perception and usage of this PHR. First of all, it is clear that a wider divulgation of this tool, perhaps through social media, is needed in order to ensure that Portuguese patients are aware of this tool. Additionally, a possible solution is to redesign *Portal do Utente,* so that this portal becomes more focused on improving patients self-management of their health instead of facilitating their administrative health-related tasks.

In a nutshell, the Personal Health Record is a critical tool to empower patients in the health care process and they are interested in using this tool. However, PHR needs to be easy to use and designed accordingly to their needs so that its adoption rate is high.

7 Limitations and Future Research

This dissertation has faced some limitations. First of all, it is important to mention the lack of available time to develop this paper. In fact, being in the workplace, writing a master thesis during free time and deliver it on time is a challenge which restricts the type of analysis that can be performed.

Concerning the survey developed, as its target was all Portuguese individuals despite of their age, education level and wage range, it would be more interesting to have a bigger sample than the one collected. Additionally, the lack of time limited the way of how to collect the data. In fact, initially the idea was to distribute the survey in primary care centers, hospitals and online. However, this survey ended up focusing solely on the internet users. Furthermore, the completion rate of the survey was lower than expected (78%), which might be related with the length of the questionnaire. Another limitation identified was the fact that the sample was not representative of the Portuguese population. The main differences were in region and education. Starting with the region, the lack of responses from Azores and Madeira Archipelagos limited the sample only to residents of Portugal Continental. Additionally, the responses from individuals living in the Lisbon Metropolitan Area were in larger scale than from the remaining NUTS II. In terms of education, there was a discrepancy in the sample as 80% had some kind of superior education and none had less than high school level, which does not match with the Portuguese reality.

Regarding future research, it would be interesting to repeat this study but with a larger sample as there might be other interesting opinions which were not identified in this dissertation. Plus, a further analysis on how the Portuguese individuals perceive *Portal do Utente*, for which purposes it is used and how could it be designed to improve the usage of all its features should be developed. A perspective of Portuguese health care professionals and other stakeholders in regard to PHR and, more precisely, to *Portal do Utente*, could be an interesting topic to be studied because part of the success of PHR depends, among others, on the willingness of doctors to communicate with their patients online. A special focus could be addressed to the differences in opinion between health care professionals and providers belonging to the NHS and to the private sector.

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Appendix 1

Survey Design

Questionário para tese de mestrado

CATÓLICA LISBON
BUSINESS & ECONOMICS

Caro participante,
No âmbito da minha Tese em Gestão da Saúde para conclusão do Mestrado em Gestão na Católica Lisbon School of Business and Economics, decidi fazer um levantamento da **opinião dos utentes portugueses quanto ao registo clínico electrónico pessoal e desenvolver estratégias para facilitar a adopção e utilização deste tipo de sistemas por parte dos mesmos**.

Nesse sentido, elaborei este questionário com o objectivo de responder às seguintes questões:

- Qual é a opinião dos utentes acerca do registo clínico electrónico pessoal;
- Quais são as motivações para acompanharem e actualizarem os seus historiais de saúde;
- Como pode o Sistema Nacional de Saúde incentivar os utentes a consultar e actualizar os registos clínicos electrónicos pessoais.

Este questionário terá a duração de aproximadamente 10 minutos.

Ao concordar em fazer parte deste estudo, compreende os objectivos deste questionário e que a sua informação poderá ser analisada para efeitos do presente estudo, sendo tratada de forma confidencial e anónima.

Agradecendo desde já a sua participação, gostaria de salientar que a sua opinião é fundamental para o sucesso deste estudo.

Atenciosamente,
Sara Hogan Silva

Em primeiro lugar, gostaria de saber um pouco mais sobre o seu estado de saúde e a utilização dos serviços de saúde.

1. Em geral, como classificaria o seu **estado de saúde**?

○ Excelente
○ Muito Bom
○ Bom
○ Satisfatório
○ Fraco

2. Sofre de alguma **doença crónica**?

○ Sim
○ Não

2.1. Se sim, qual? (em caso de ter mais do que uma, referir a principal)

____

3. Durante o último ano, quantas **visitas fez às seguintes unidades de saúde**:

	Nenhuma	1	2-3	Mais de 3
Centro de Saúde (incluindo médicos e enfermeiros)	○	○	○	○
Médico especialista do SNS (p.e. dermatologista, ginecologista, oftmalmologista)	○	○	○	○
Médico especialista do sistema privado	○	○	○	○
Urgências	○	○	○	○
Hospital (internamento)	○	○	○	○

4. Em geral, o quão **satisfeito** está com a qualidade do serviço de saúde recebido ao longo dos últimos 5 anos?

○ Muito satisfeito
○ Satisfeito
○ Indiferente
○ Insatisfeito
○ Muito Insatisfeito

5. Costuma ter **problemas em compreender** os seus médicos quando falam sobre a sua saúde?

○ Sempre
○ Frequentemente
○ Por vezes
○ Ocasionalmente
○ Nunca

5.1 Caso tenha algum problema em compreender, qual a razão?

____

6. Qual das seguintes frases **melhor descreve a sua forma de tomar decisões** relativamente à sua saúde? Selecione apenas uma:

○ O meu médico dá recomendações, mas eu tomo as minhas próprias decisões relativamente à minha saude.
○ As decisões são tomadas em conjunto com o meu médico.
○ Deixo que seja o meu médico a tomar a melhor decisão para a situação em questão.
○ Outra: _____________________

As seguintes questões estão relacionadas com o uso de computadores, tablets e internet no dia-a-dia.

7. Tem algum **computador ou tablet**, com internet, disponível em casa ou no seu local de trabalho?

○ Sim
○ Não

8. Com que **frequência** utiliza a Internet?

○ Várias vezes por dia
○ Uma vez por dia
○ Uma vez por semana
○ Uma vez por mês
○ Raramente ou nunca

9. Algum dos seus médicos **utiliza** um computador/tablet para aceder ao seu registo clínico?

○ Sim
○ Não
○ Não sei

As seguintes questões estão relacionadas com os registos clínicos electrónicos pessoais.

“**O registo clínico electrónico pessoal trata-se de uma aplicação electrónica ou website por meio do qual os utentes podem aceder, gerir (por exemplo, marcar consultas) e partilhar as suas informações de saúde com outras pessoas autorizadas, num ambiente privado, seguro e confidencial**.” *(fonte: Markle’s Foundation)*

10. Conhecia este conceito?

○ Sim
○ Não

11. Em que medida concorda ou discorda com a seguinte afirmação: **Eu estou interessado/a em utilizar o registo clínico electrónico pessoal na Internet para aceder à minha informação clínica** (por exemplo historial clínico) e gerir a minha saúde.

○ Concordo Totalmente
○ Concordo em parte
○ Não concordo nem discordo
○ Discordo em parte
○ Discordo Totalmente

11.1 Caso não concorde, porque razão razão não estaria interessado em utilizá-lo?

____

12. Avalie de 1 a 5 (em que 1 significa "não é importante" e 5 "muito importante") a **importância** que teria para si a disponibilidade dos seguintes tipos de informação no seu registo clínico electrónico pessoal:

	1	2	3	4	5
Alergias	○	○	○	○	○
Resultados de exames (p.e. análises sanguíneas, raios-X)	○	○	○	○	○
Boletim de vacinas	○	○	○	○	○
Medicação tomada nos últimos anos ou que está a tomar actualmente	○	○	○	○	○
Lista de médicos e unidades de saúde visitadas	○	○	○	○	○
Historial de família de doenças	○	○	○	○	○
Diagnósticos	○	○	○	○	○
Consultas, cirurgias e procedimentos médicos efectuados	○	○	○	○	○
Hábitos de saúde (p.e. execício físico, fumador/a)	○	○	○	○	○
Dicionário da Saúde (definições claras e simples de conceitos médicos)	○	○	○	○	○

13. Para cada uma das opções, por favor indique se se trata de uma actividade que já faz actualmente, não faz mas gostaria de fazer, ou que não quer fazer **pela Internet**:

	Já faço actualmente pela Internet	Gostaria de poder fazer pela Internet	Não quero fazer pela Internet
Ver o meu historial clínico, resultados de exames e lista de medicamentos a tomar actualmente	○	○	○
Adicionar notas ao meu historial clínico	○	○	○
Marcar consultas e solicitar prescrições de medicamentos	○	○	○
Comunicar com o meu médico e/ou receber relatórios do meu médico por e-mail	○	○	○
Encontrar um médico que aceite o meu seguro de saúde, e preencha todos os formulários solicitados pela seguradora	○	○	○
Criar alertas/lembretes para serviços de saúde preventivos (p.e. tomar vacinas, efectuar testes ao colesterol)	○	○	○
Aceder ao registo clínico electrónico de um familiar que esteja a meu cuidado.	○	○	○
Entrar em contacto com outros utentes que tenham problemas de saúde similares com os meus (p.e. fóruns de discussão, grupos de apoio)	○	○	○
Receber materiais educacionais relacionados com a minha saúde	○	○	○
Elaborar o meu testamento vital (documento onde pode registar os cuidados que pretende ou não receber e permite também a nomeação de um procurador de cuidados de saúde)	○	○	○

14. Com que **frequência** pensa que iria aceder ao registo clínico electrónico pessoal para ver a sua informação médica e gerir a sua saúde (p.e. confirmar marcações, comunicar com médicos, actualizar hábitos de saúde)

○ Diariamente
○ Semanalmente
○ Mensalmente
○ Uma vez a cada 3 a 6 meses
○ Raramente ou nunca

15. Em que medida acredita que os **registos clínicos electrónicos pessoais** para aceder à sua informação médica e gerir a sua saúde pela Internet iriam **afectar**:

	Melhorar significativamente	Melhorar ligeiramente	Não afectar	Piorar ligeiramente	Piorar significativamente
A segurança e privacidade dos meus dados	○	○	○	○	○
Comunicação com os médicos	○	○	○	○	○
Compreensão da minha saúde	○	○	○	○	○
Sentido de controlo sobre a minha saúde	○	○	○	○	○
Preocupações quanto à minha saúde	○	○	○	○	○
Tomada de decisões livres de erros por parte dos meus médicos	○	○	○	○	○
Satisfação com a minha saúde	○	○	○	○	○
Qualidade da minha saúde	○	○	○	○	○
Gastos com saúde	○	○	○	○	○
Outra:	○	○	○	○	○

16. Na sua opinião, quão fácil ou difícil seria para si **utilizar** os registos clínicos electrónicos pessoais?

○ Muito difícil
○ Difícil
○ Ligeiramente difícil
○ Fácil
○ Muito Fácil

17. A quem daria **autorização** para aceder ao seu registo clínico electrónico pessoal? Seleccione todas as aplicáveis

☐ Familiares ou amigos designados
☐ Médico de família
☐ Outros médicos ou unidades de saúde que cuidem de mim (numa clínica, urgência, ou hospital)
☐ Seguradora
☐ Empregador
☐ Organismos do Governo
☐ Não daria permissão a ninguém

Por fim, gostaria de saber se conhece uma das iniciativas do Ministério da Saúde relativamente aos registos clínicos electrónicos pessoais.

18. Conhece o **Portal do Utente** - Plataforma de Dados da Saúde?

○ Sim
○ Não *(passe à pergunta 22)*

19. Está registado?

○ Sim
○ Não *(passe à secção dados do inquirido)*

20. E utiliza?

○ Sim
○ Não

21. Qual o seu grau de satifação com o Portal? *(após esta questão passe para a secção dados do inquirido)*

○ Muito Satisfeito/a
○ Satisfeito/a
○ Indiferente
○ Insatisfeito/a
○ Muito Insatisfeito/a

22.

Histórico Clínico

Conheça a sua história clínica e consulte ao longo do tempo as suas interações com Serviço Nacional de Saúde

O Portal do Utente trata-se de uma ferramenta gratuita que permite, via internet, monitorizar a sua saúde e aceder facilmente aos serviços disponibilizados pelo SNS (Sistema Nacional de Saúde).

Funcionalidades:

- Marcar consultas
- Consultar Testamento Vital
- Renovar a medicação crónica
- Pedir isenção de taxas moderadoras
- Consultar os dados do utente
- Visualizar o Cartão de Pessoa com Doença Rara
- Partilhar informação com profissionais de saúde
- Consultar os registos clínicos
- Monitorizar a saúde
- Aceder ao eBoletim de saúde infantil

Estaria interessado/a em registar-se neste Portal?

○ Sim

○ Não

23. Caso tenha respondido não, qual a razão?

____

Dados do Inquirido

Idade: _____

Sexo:
❍ Masculino
❍ Feminino

Residente em:
❍ Norte
❍ Centro
❍ Área Metropolitana de Lisboa
❍ Alentejo
❍ Algarve
❍ Região Autónoma dos Açores
❍ Região Autónoma da Madeira

Habilitações literárias (mais recente):
❍ Ensino Básico
❍ Ensino Secundário
❍ Licenciatura
❍ Pós-graduação
❍ Mestrado
❍ Doutoramento ou mais

Rendimento médio mensal individual (líquido):
❍ Inferior a 500€
❍ Entre 501€ e 1.000€
❍ Entre 1.001€ e 2.000€
❍ Entre 2.001€ e 4.000€
❍ Entre 4.001€ e 6.000€
❍ Superior a 6.000€

Appendix 2

List of Associations which shared the survey

Among the 22 organizations contacted, 5 agreed to share the survey with their network:

- Associação Portuguesa de Apoio à mulher com Cancro da Mama
- Sociedade Portguesa de Esclerose Múltipla
- Comunidade Idosos Activos
- Fundação SNS
- Apoio à vida

Appendix 3

Demographics of the Sample

Characteristics	Count	Percentage
Age		
18-24	99	40%
25-34	45	18%
35-44	31	13%
45-54	34	14%
55-64	24	10%
65-74	10	4%
75 or more	3	1%
Gender		
Male	84	33%
Female	168	67%
Residence		
North	38	15%
Centre	50	20%
Lisbon Metropolitan Area	154	62%
Alentejo	7	3%
Algarve	1	0%
Education		
Elementary School	0	0%
High School Graduate	50	20%
Bachelor Degree	114	46%
Postgraduate	52	21%
Master Degree	23	9%
PhD or more	9	4%
Wage		
Below 500€	68	30%
Between 501€ e 1.000€	65	28%
Between 1.001€ and 2.000€	75	33%
Between 2.001€ and 4.000€	20	9%
Between 4.001€ and 6.000€	2	1%
Higher than 6.000€		0%

Appendix 4

Health Status and interaction with health care providers

Variable	Count	Percentage
Perceived Health Status		
Excellent	26	10%
Very Good	101	40%
Good	80	32%
Fair	37	15%
Poor	8	3%
Chronic Disease		
Yes	72	29%
No	180	71%
Comprehension of information provided by doctors		
Always	4	2%
Frequently	12	5%
Sometimes	52	21%
Occasionally	92	37%
Never	92	37%
Satisfaction with the quality of health care service		
Very Satisfied	29	12%
Satisfied	159	63%
Indifferent	31	12%
Dissatisfied	29	12%
Very Dissatisfied	4	2%
Who takes the decision		
Individual takes the decision	26	10%
Decisions as a team	145	58%
Doctor takes the decision	79	31%
Health care decisions (other)	2	1%

Visits to health care units in the last year

	None	One	2-3	More than 3
Primary Care Visits	37%	21%	29%	13%
Secondary Care Visits	54%	18%	18%	10%
Emergency Room Visits	60%	21%	15%	4%
Inpatient Care Visits	90%	8%	2%	0%
Private Practice Physicians Visits	38%	28%	20%	14%

Appendix 5

Internet Habits

Characteristics	Count	Percentage
Internet Usage		
Many times per day	240	95%
Once a day	9	4%
Once a week	0	0%
Once monthly	1	0%
Rarely or not at all	2	1%
Use of laptop/tablet by physician		
Yes	202	80%
No	10	4%
I don't know	40	16%

Appendix 6

Awareness of the concept and Willingness to use PHR

Answers	Count	Percentage
Awareness of PHR		
Yes	128	51%
No	124	49%
Willingness		
Strongly Agree	151	60%
Agree	70	28%
Neutral	16	6%
Disagree	11	4%
Strongly Disagree	4	2%
Frequency of Access		
Daily	3	1%
Once a week	25	10%
Once a month	105	42%
Once every 3 to 6 months	104	41%
Rarely or not at all	15	6%
Ease of use		
Very Difficult	1	0%
Difficult	4	2%
Slightly Difficult	19	8%
Easy	130	52%
Very Easy	98	39%

Appendix 7

Potential Effects of a PHR

Potential Effects of a PHR

	Improve Significantly	Slightly Improve	Not affect	Slightly Worsen	Worsen Significantly	Total
Security and privacy of my medical information	35	28	78	72	37	250
Communication between my doctors and myself	117	95	26	9	5	252
My understanding of my own health	100	98	48	4	0	250
My sense of control over my own healthcare	126	88	35	2	1	252
My worries acout my own healthcare	81	82	82	5	1	251
The safety of my care (freedom from errors)	67	79	92	7	6	251
My satisfaction with my healthcare	78	85	86	1	2	252
Quality of my healthcare	82	84	84	0	2	252
Costs of my healthcare	77	60	105	7	2	251
Other	9	3	9	0	1	22

Potential Effects of a PHR

	Improve Significantly	Slightly Improve	Not affect	Slightly Worsen	Worsen Significantly	Total
Security and privacy of my medical information	14%	11%	31%	29%	15%	1
Communication between my doctors and myself	31%	24%	42%	3%	1%	1
My understanding of my own health	33%	33%	33%	0%	1%	1
My sense of control over my own healthcare	41%	14%	41%	0%	5%	1
My worries acout my own healthcare	32%	33%	33%	2%	0%	1
The safety of my care (freedom from errors)	46%	38%	10%	4%	2%	1
My satisfaction with my healthcare	27%	31%	37%	3%	2%	1
Quality of my healthcare	31%	34%	34%	0%	1%	1
Costs of my healthcare	40%	39%	19%	2%	0%	1
Other	50%	35%	14%	1%	0%	1

Appendix 8

Preferences for health care related activities done online

Preferences for health care related activities done online

	I do this online already	I would like to do this online	I do not want to do this online	Total
Communicate with other people with similar health problems	11	150	91	252
Advance health care directive	8	175	69	252
Add notes to my medical record	6	194	52	252
Receive educational materials related to my health	15	185	52	252
Find a physician who accepts my insurance, file insurance claims, and fill out paperwork before and after a physician visit	28	175	49	252
Access my child’s or parent’s medical records if I am their primary caretaker	9	218	25	252
View my medical records, test results, and lists of medications I am taking	24	207	21	252
Communicate with my doctor and/or receive reports from my doctor by e-mail	28	200	24	252
Sign up for reminders for preventative health services	20	219	13	252
Request medical appointments and prescription refills	63	178	11	252

Preferences for health care related activities done online

	I do this online already	I would like to do this online	I do not want to do this online	Total
Communicate with other people with similar health problems	11	150	91	252
Advance health care directive	8	175	69	252
Add notes to my medical record	6	194	52	252
Receive educational materials related to my health	15	185	52	252
Find a physician who accepts my insurance, file insurance claims, and fill out paperwork before and after a physician visit	28	175	49	252
Access my child’s or parent’s medical records if I am their primary caretaker	9	218	25	252
View my medical records, test results, and lists of medications I am taking	24	207	21	252
Communicate with my doctor and/or receive reports from my doctor by e-mail	28	200	24	252
Sign up for reminders for preventative health services	20	219	13	252
Request medical appointments and prescription refills	63	178	11	252

Preferences for health care related activities done online

	I do this online already	I would like to do this online	I do not want to do this online	Total
Communicate with other people with similar health problems	4%	60%	36%	100%
Advance health care directive	3%	69%	27%	100%
Add notes to my medical record	2%	77%	21%	100%
Receive educational materials related to my health	6%	73%	21%	100%
Find a physician who accepts my insurance, file insurance claims, and fill out paperwork before and after a physician visit	11%	69%	19%	100%
Access my child’s or parent’s medical records if I am their primary caretaker	4%	87%	10%	100%
View my medical records, test results, and lists of medications I am taking	10%	82%	8%	100%
Communicate with my doctor and/or receive reports from my doctor by e-mail	11%	79%	10%	100%
Sign up for reminders for preventative health services	8%	87%	5%	100%
Request medical appointments and prescription refills	25%	71%	4%	100%