Development of a mobile health condition enhancer tool for chronic patients in Azores

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Carolina Madeira Ramos do Carmo

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Tese de Mestrado

Carolina Madeira Ramos do Carmo

Orientadores

Professora Doutora Ana Maria Loureiro da Seca

Doutor Darius Adam Rohani

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Summary

Chronic diseases are prevalent in more than 50% of the population of the Autonomous Region of the Azores (RAA) leading to a decreasing self-perception of well-being across this population in the last decade.

Self-management is considered as the most effective first-line treatment for these conditions and mHealth apps have shown promising results to support this approach. Furthermore, this digital solution enables tracking of health data to be shared, at any time, with clinicians for therapeutics improvement and better health outcomes. Overall, mHealth tools have the potential to increase efficiency of healthcare systems resources.

In this master thesis project, a mobile app, Bem Me Quero (BMQ) - Açores, is designed guided by data-driven insights collected through online questionnaire as well as workshops with both chronic patients and related clinicians. The results showed that 80% of the population of chronic patients studied consider mHealth smartphone apps as an useful tool to enhance their health condition. Features like tracking of symptoms, healthcare advice, medication reminders and a forum for health-related topics were considered as the most valued to support patients in their daily challenges. Additionally, it was revealed that an user-friendly customizable design is paramount to guarantee these tools fulfil their objectives.

The results of this thesis shed a light regarding user experience optimization and features of a mobile App to support and improve the self-perception of well-being for chronic patients in Azores on a daily basis.

Keywords: chronic disease, health literacy, mHealth, medication adherence, natural products, digital health

Resumo

As doenças crónicas são prevalentes em mais de 50% da população da Região Autónoma dos Açores (RAA) levando, na última década, a uma decrescente auto-percepção do bem-estar nesta população.

A autogestão é considerada como o procedimento de primeira linha mais eficaz para estas condições e as aplicações mHealth têm mostrado resultados promissores para apoiar esta abordagem. Além disso, esta solução digital permite o rastreio de dados de saúde a serem partilhados, em qualquer altura, com clínicos para a melhoria da terapêutica e melhores resultados de saúde. Globalmente, as ferramentas mHealth têm o potencial de aumentar a eficiência dos recursos dos sistemas de saúde.

Neste projecto de tese de mestrado, uma aplicação móvel, Bem Me Quero (BMQ) - Açores, é desenhada tendo em conta os dados recolhidos através de questionários online, bem como seminários com doentes crónicos e clínicos da área. Os resultados mostraram que 80% da população de doentes crónicos estudados consideram as aplicações smartphone mHealth como uma ferramenta útil para melhorar o seu estado de saúde. Funções como o rastreio dos sintomas, conselhos de cuidados de saúde, lembretes de medicação e um fórum para tópicos relacionados com a saúde foram consideradas como as mais valorizadas para apoiar os doentes crónicos nos seus desafios diários. Além disso, os resultados obtidos revelaram que um design de fácil utilização e personalizável é primordial para garantir que estas ferramentas cumpram os seus objectivos.

Os resultados desta tese de mestrado clarificam as caraterísticas de uma aplicação móvel após a sua otimização baseada na experiência dos utilizadores, que permitem apoiar e melhorar, numa base diária, a auto-perceção do bem-estar dos pacientes crónicos nos Açores.

Palavras-chave: doença crónica, literacia de saúde, mSaúde, aderência a medicação, produtos naturais, saúde digital

Preface

This thesis has been prepared over twelve months at the Faculty of Sciences and Technology, at the University of Azores, UAc, in fulfilment for the degree Master of Biomedical Sciences, MSc. The thesis was done under supervision of Professor Ana M.L. Seca from cE3c - Centre for Ecology, Evolution and Environmental Changes/Azorean Biodiversity Group & University of Azores (UAc) , and Dr. Darius A. Rohani at the Department of Health Technology, Technical University of Denmark (DTU).

This thesis aims at describing the background, methods, main results, conclusions and perspectives of the work done for this Master's degree project with the title "Development of a mobile health condition enhancer tool for chronic patients in Azores".

Ponta Delgada, October 31, 2021

Carolina Carmo (2019104544)

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I would like to extend my sincere thanks for the support of the Regional Directorate of Health, Direção Regional de Saúde, for the endorsement of this project and for disseminating the survey across all the healthcare centres (USIs) in the archipelago. I gratefully acknowledge also the effort of the regional associations Assoc. Portuguesa Insuficientes Renais (APIR) and Assoc. de Doentes de Dor Crónica dos Açores (ADDCA) to disseminate the survey across the population and finding patients for the workshops. I cannot begin to express my gratitude to Dra. Maria Teresa Flor de Lima and Prof. Joaquim Tomé from the association ADDCA for their enthusiasm and continuous support throughout the project when involvement of patients and healthcare providers was necessary. An extra thanks to Dra. Maria Teresa to invite participants from other chronic disease regional associations and to share invitations to relevant conferences, meetings and symposiums in the area. Many thanks to the patients and participants of the survey for their time and inputs. Your contributions were instrumental in this research and hopefully to promote great changes in the healthcare system of the Azores.

Most importantly, none of this could have happened without the support of my family and friends, that offered me their encouragement through phone calls, messages every week - despite my own limited devotion. This thesis stands as a testament to your unconditional encouragement, support and love.

Contents

Acronyms

App	Smartphone Mobile Application iii,2,4,5,12,13,16,19,24-27,30,33, 35,36,37,39-51,54-59
BMI	Body Mass Index 16,29,31
BMQ	Bem Me Quero
CDC	Centers for Disease Control and Prevention 16
COPD	Chronic Obstructive Pulmonary Disease 7
CV	*Curriculum Vitae* 23
GHQ	General Health Questionnaire 19,33
HCD	Human Centred Design 2,12-16,25,37,47
high-fi	High-fidelity 27,47,50,57
HIV/AIDS	Acquired ImmunoDeficiency Syndrome 7
HL	Health Literacy 16-18,53
HLQ	Health Literacy Questionnaire 16-18,35
HLS	Health Literacy Survey 17,18,34,54
ICD	International Classification of Diseases 8
InReS	Regional Health Survey 7,54 Inquérito Regional de Saúde
ISO	International Organization for Standarization 12,14
low-fi	Low-fidelity 26,38
MMAS8	Morisky Medication Adherence Scale - 8 16,32,33
NP	Natural Products 16,32,33
RAA	Autonomous Region of Azores iii,v,1,2,4,5,7,11,13,15,16,19,31,33, 34,36,53,54,57,59
RQ	Research Question 2,4,53
SNS	National Healthcare System 7 Serviço Nacional de Saúde
SRQ	Sub-Research Question 2,4,15,53,54
UCD	User Centred Design 2,12,13,56
UI	User Interface 13
USI	Island Health Centre ix,xii,4,19,22,23,29,57 Unidade Saúde da Ilha
UX	User Experience 12,13
WHO	World Health Organization 1,2,7

CHAPTER 1

Introduction

Chronic diseases are not only the global leading cause of morbidity and mortality but also represent high demand on healthcare resources and national expediture [1].

1.1 Context and Motivation

In 2005, it was estimated that 54.4% of the residents in the Autonomous Region of the Azores (RAA), aged between 25 and 74 years old, self-appreciated their health condition as Good or Very Good. However, in the last decade, this value decreased 5.9 points to 48.5%. Thus, more than half of the population - 51.5% - consider it reasonable (43.5%), bad (6.3%) or very bad (1.5%). Several chronic pathologies prevalent in the RAA population as well as ageing population could explain this unfavourable self-perception of health [2].

This demographic pattern changes constitute an increased pressure on resources of healthcare systems in Azores [3]. To respond to the growing demands on resources, healthcare systems are undergoing a change of paradigm. The future of healthcare is leading to a decentralised model supported by rapidly advancing technology. The framework for the future healthcare system is known as P4 healthcare - Predictive, Preventative, Personalised and Participatory care – with patient involvement in their own health [4]. On April, 28th, 2021, the Government of the Azores organized an online conference called 'Digital Innovation Roadshow' to share its intention to digitalize the regional health system with the *"objective of substantially changing the relationship between the disease, the patient and the Regional Health Service"* [5].

Among the different digital solutions, mobile health – also known as mHealth - tools to support the future of healthcare systems have been increasing in the last decade. The abilities of mHealth apps have shown to be especially helpful for patients with chronic diseases which due to long duration pose major healthcare system and economic burden [6]–[9]. Yet, in 2011 and again in 2019, the World Health Organization (WHO) recommended further research for evidences to prove the effectiveness of mHealth tools to improve healthcare systems [10], [11]. The potential of mHealth tools to transform the future of healthcare systems is undermined if only access to mHealth tools is taken into account. Although today, more than 300,000 health-related apps are available, there is limited uptake of these apps and most do not manage to maintain a double-digit user retention rate after 30 days of installation [12]. Continuous use and engagement are paramount to motivate positive behaviour

change among chronic ill individuals [1]. Thus, literature promotes that the perspectives of patients as well as of health care practitioners must be considered during the design and development of mHealth tools [13] to guarantee its effectiveness on healthcare system resources optimization.

1.2 Objectives

Given the challenges of continuous usage and engagement of mHealth tools, this project aims at considering human and user-centred design, known as HCD and UCD, principles to design a mobile tool to transform personal health management in chronic patients in the RAA population. This approach implies an iterative design process, where user requirements and prototypes are updated taking into account end-users feedback. In this way, this project aims at fitting the target user context and, thus, fulfilling the aforementioned intentions of the Government of the Azores and the WHO [5], [10], [11].

1.2.1 Research Questions

In this master thesis project, a mobile app to tackle the aforementioned challenges while ensuring user engagement and offer unique opportunities for chronically ill patients in the RAA population is developed by using HCD and UCD strategies.

Tracking symptoms, appointment, and medication reminders as well as improvement of health literacy levels and combination with literacy on natural products are among the most promising features for chronic patients well-being improvement and were contemplated in the development of the app.

To support this hypothesis, this work shall be answering to the following main research question (RQ):

- **RQ** What is the design of a smartphone-based system that support chronic patients' in their everyday life in Azores?

  Three sub-research questions (SRQ) pave the way to answer this question:

- **SRQ1** How do chronic patients in RAA manage their condition? What are their main challenges?
- **SRQ2** What is the current health and natural products literacy level among the RAA population?
- **SRQ3** What design and features are perceived as relevant among chronic patients to increase health related quality of life?

In sum, this work shall present knowledge on the mobile tool features necessary to support people with chronic diseases in the RAA as well as show its feasibility to meet their needs for quality of life improvement. The methods employed to answer

the research questions and fulfil the project objective are further described in the following section.

1.3 Research Methods

A survey has been designed and disseminated across the chronic patients in the RAA to obtain knowledge on their challenges and needs for self-management chronic illness, in line with SRQ1 and SRQ2. The study was approved by the institutional review Ethics board of the University of Azores as well as the Regional Health Directorate and in four of its Health Units (USI) of the nine islands. Data were collected at the USIs via healthcare professionals as well as regional associations of the different chronic conditions between January 2021 and September 2021. In parallel with the survey, a thorough literature review was performed to elucidate on prior work on mHealth apps solutions conceived with focus on chronic patients concluding the *RESEARCH* phase in Figure 1.1.

Based on the outputs of the previous step, the brainstorming of the concept of Bem Me Quero - Açores (BMQ) app launched. A kickstart experiment design was held online on July, 2nd, 2021 together with 3 chronic patients and 1 practitioner of the RAA to further adjust the initial specifications. Finally, in the second iteration, a high-fidelity prototype of the app has been designed and its usability evaluated as a case study on a chronic patient diagnosed with chronic pain, and a physician from the department of palliative care at the hospital of St Louis on October, 8th, 2021 to further improve the design and features of the BMQ-app and assess the ability of the proposed solution to improve the well-being of chronic patients and optimize healthcare systems resources. The later provided the evidences to answer SRQ3.

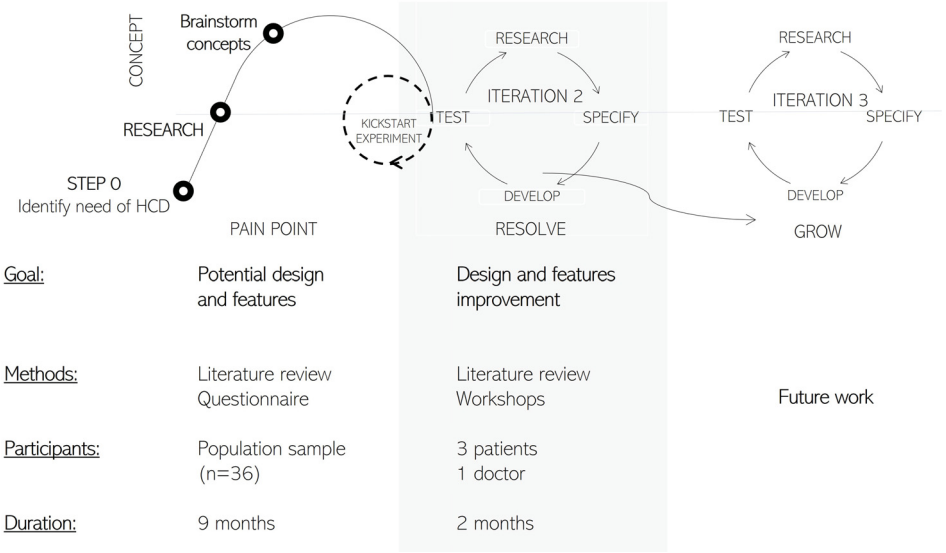

Figure 1.1: Overview of the thesis work.

1.4 Research Contributions

The main contribution of this thesis is the concept and design of the Bem Me Quero (BMQ) - Açores app. This app was designed together with chronic patients and practitioners to help in the patients' daily health-related challenges.

The selected features of this system enable the chronic patients to (i) monitor and find interactions between different trackers, (ii) to be reminded about prescribed medication, medical appointments and registration of health-related data, (iii) to follow a self-management improvement program and (iv) to engage in discussions with other patients in a forum with information validated by health professionals.

BMQ - Açores app is designed for patients as primary user and therefore, the trackers can be selected according to their preferences. However, it also offers the possibility to share the data collected with practitioners, which will potentially unveil new insights into chronic diseases. Thus, this work presents knowledge on the mobile tool features necessary to support both people with chronic diseases in the RAA as well as to tackle the challenges of the healthcare system.

The design consists of a high-fidelity prototype of BMQ - Açores developed using Figma. It can be found at:

https://www.figma.com/file/m8YJ8todfcAXE5ECZgrXxe/v0?node-id=0%3A1

1.5 Thesis Structure

This thesis is structured as follows:

- In chapter 2, **Background and state-of-the-art review**, the literature review performed prior to the design activities is presented. The methodological frameworks are also discussed.
- In chapter 3, **Investigative methods**, outlines the methodology for the questionnaire design, data collection phase and statistical analysis and describes the prior work review methodology.
- In chapter 4, **Development of a mHealth tool**, presents the rationale and design methods for the mobile application (app).
- In chapter 5, the **Results** of the previous two chapters are presented.
- In chapter 6, the **Discussion** chapter, the sub-research questions are answered by the interpreting and discussing the results. It synthesizes the answers to the main research question (RQ) into a coherent discussion. In the section *Future Work* the paths that are worthwhile for future research activities are suggested disclosing the RQ.
- **Conclusions** sums up and concludes this thesis.

CHAPTER 2

Background and state-of-the-art review

2.1 Chronic diseases in RAA population

The last Regional Health Survey (InReS) revealed that more than half (51.5%) of the population aged between 25 and 74 years old in the autonomous region of the Azores (RAA) consider their health condition "reasonable", "bad" or "very bad". The proportion of people referring to their state of health as "good" or "very good" decreases with the increase of age [2]. Additionally, it detected that several chronic pathologies are prevalent in the population. Pathologies – lasting at least a year or permanent - like pre- and obesity (64.5%), psychological changes (32%), high blood pressure (28.3%), allergies (26%), chronic pain (23.6%), rheumatic illness (22.6%), genetic diseases (11%), and diabetes (9.9%) [2] could explain the unfavourable self-perception of health [14].

The term *"chronic disease"* presents a large degree of terminology variation across countries and professional health organisations [15]. For the sake of clarity in this work chronic disease is defined as:

> *"physical and/or mental health conditions that restrict daily activities and require ongoing medical attention as well as patient self-management for at least one year or more - in a continuous or reoccurring way"*

This definition is inline with the WHO's interpretation of the term but aims at define the term "chronic/long-term" with a specific time span. Besides, the definition proposed includes chronic conditions legally but dispersedly recognised in the Portuguese national health system (SNS), as: *asthma, diabetes, cancer, cardiovascular diseases, chronic obstructive pulmonary disease (COPD), rheumatic illness, visual impairment, obesity, acquired immunodeficiency syndrome (HIV/AIDS), Alzheimer and other dementias* [16]–[18], yet also intends to bring awareness to other chronic health problems that are still not legally recognized. For example, chronic primary pain included as a chronic condition in this work and only recently acknowledged in the International Classification of Diseases (ICD-11) of WHO and scheduled to go into effect in the year 2022 [19].

The demographic pattern changes, and older people being a growing part of the population put pressure on resources of healthcare systems. For example, near 50% of chronic patients struggle to take medications as prescribed. Several factors can affect the adherence from trivial reasons as forgetfulness and social embarrassment, to co-morbidities, financial charges, drug-related adverse side effects, complex medication schedule and/or poor health literacy. The non-adherence has negative impact on the well-being of patients, the therapeutic outcome as well as in the number of hospitalizations and related costs [6], [20].

2.2 Role of mHealth apps for chronic patients in the future Azorean healthcare system

The rapid development of technology unlocks opportunities to conquer the challenges presented above. Feasibility studies of mobile health – known as mHealth - tools to support the future of healthcare systems have been increasing in the last decade. A literature review search using the term mHealth [title/abstract/author/keywords] on Web of Science database done in October 2020 showed the records rose from 19 in 2010 to 1205 in 2019 (Figure 2.1, blue line).

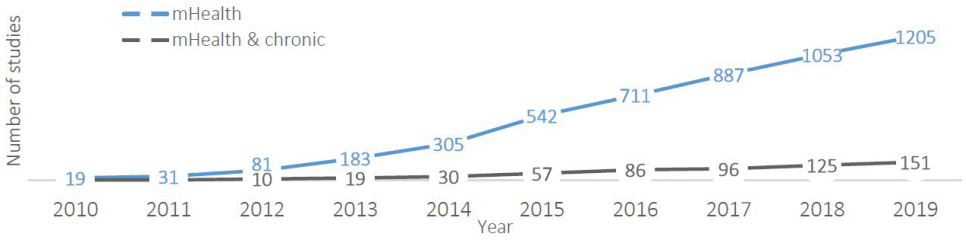

Figure 2.1: Scientific studies on the database Web of Science with the search criteria: mHealth and mHealth AND chronic.

The mHealth tools may enable patient information registration to support patients and caregivers from various conditions while optimizing healthcare system resources. Current literature supports the use of mHealth solutions showing benefits in each step of the healthcare process - i.e. prevention, diagnosis, decision-making, treatment, and follow-up. In such manner, they point to a revolution in healthcare systems that is predictive, preventive, personalized and participatory (P4 healthcare) [21].

Thus, the abilities of mHealth tools have shown especially useful for chronic patients. Consequently, the number of studies related to mHealth and chronic diseases grows (Figure 2.1, black line).

In 2020, Aapro *et al.* systematically reviewed 66 studies scoping the role of digital health in chronic oncology patients [6]. The benefits and limitations of these solutions on all the stakeholders in a healthcare system are illustrated in Figure 2.2. The main benefits are the promotion of a healthcare system patient-driven as well as its resources optimization. The limitations are mainly users' difficulties dealing with technology, new practices, regulatory constraints and potential development costs.

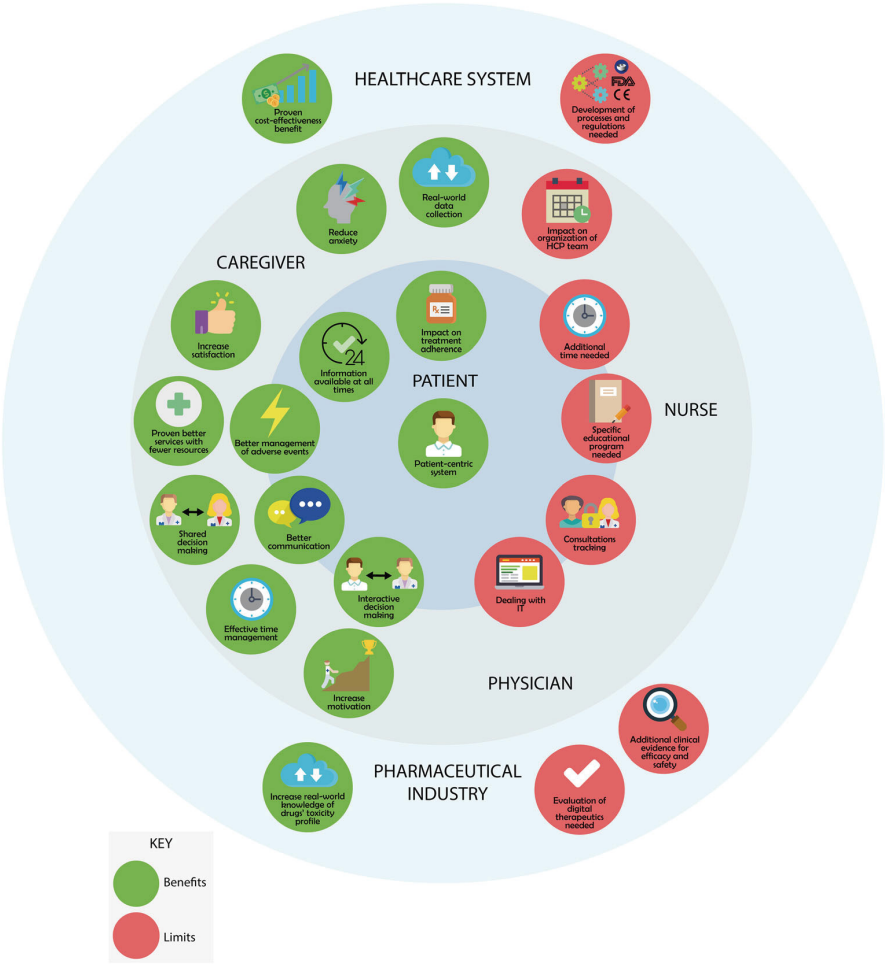

Figure 2.2: Benefits and limitations of digital health solution in the healthcare system [6].

Furthermore, mHealth has the potential to extend healthcare services to remote and hard-to-reach areas in the Azores where under-served population live - via smart-

phones. The ownership of this technology is increasing rapidly worldwide across all strata of society [8]. Therefore, this work is specifically focused on mHealth applications (apps) which are smartphone applications that collect and/or share healthcare information and/or health services [22]. Overall, it should improve the patients' health literacy.

2.2.1 Relevance of health literacy in chronic condition care

In the 1970s the term *Health literacy* was introduced. It concerns the capacity of a person to assess, understand and apply health-related information to take care of itself and its family and community by both promoting health and preventing disease [23]. In 2020, Aaby *et al.* provided evidence that long-term illness is related to specific health literacy challenges such as active self-management [14]. This confirmed past studies, including the Portuguese Health Literacy Survey showing that negative self-perception state of health was more frequent in individuals with lower health literacy [24]. Hence, the development of effective solutions to promote health literacy is paramount to improve quality-of-life of chronic patients.

According to the above mentioned reviews, mHealth tools should offer solutions to address the key daily challenges of patients, among them promote health literacy. These tools should be able to support on therapeutic adherence, symptom management, give advice aligned with medical guidelines, medication reminders, nutritional information, resources for social support, and coping strategies. Several studies have demonstrated the effectiveness of mHealth in chronic condition care. Those studies made evident improvements in physical functioning, adherence to prescribed medication and/or symptoms mitigation for diverse chronic conditions [7]–[9].

2.2.2 Natural Products (NP) - Drug synergies in chronic patients in RAA

Another opportunity to boost health for chronic patients in RAA is to increase awareness of pleiotropic of NP. Pre-clinical and clinical trials on additive and synergistic effects between pharmaceutical drugs and selected NP have shown improved therapeutic efficacy and safety in chronic conditions [20].

Besides, NP can complement pharmacotherapies as psychobehavioural incentives. Especially in the remission period (inactive-disease state), engaging habit-forming mechanisms and actively involving patients in shared-decision making on the clinically-efficacious self-care behaviour, such as dose of the natural product or other, play a key role for illness self-management and self-efficacy which lead to activate the reward system. mHealth tools have been applied to further research on valuable interactions by tracking health information from patients and sharing with health care providers [20].

The Azores being a region with NP with attractive and unique functional properties should be seeking to highlight its added value to the population. Several studies

from the University of Azores (UAc) research groups on dairy products and its by-products [25]; Azorean tea [26]; pineapple and other, if disseminated adequately could impact positively health and well-being of the population. Besides the consequent reduction in healthcare spending, an attractive potential for Azorean competitiveness while addressing societal challenges could be achieved.

2.3 mHealth tools challenges

There are today more than 300,000 mHealth apps available in different app stores [27]. Yet, the successful adoption of mHealth tools has been limited. While mHealth apps have shown to efficiently support chronic patients' good health and improved disease management, previous studies have revealed a significant degree of abandonment due to *"lack of time for entering the data; lack of interest; (...) hidden costs (...) after trial period; difficulties using them (...) or data being shared in social networks (...)"* [28].

Different qualitative and empirical studies have assessed mobile app abilities and investigated the challenges and outcomes faced by researchers, patients and practitioners [7]–[9]. In 5 systematic reviews on mobile apps for chronic patients support, it was found that the main challenges are in developing and implementing digital solutions that incorporate health professionals inputs, while meeting patients needs to ensure optimal management of chronic diseases. It is fundamental to include app usability evaluation as well as resilient software architectures [4], [6]–[9].

Consequently, further research is vital to find effective apps to promote a P4 healthcare system.

2.3.1 Methodological frameworks

"Bad experience" has been the leading reason for users to uninstall apps despite their positive impact on healthcare. An integrative review including 69 papers on successful experiences with mHealth apps suggests the obvious need for involving all stakeholders from the early stages of the design process to ensure good usability and user experience (UX) as other approaches that exclude them in the development phase have been seen to fail [28].

As per ISO standard 9241-210:2019, otherwise known as "Human-centered design for interactive systems", usability is defined as:

> *The extent to which the system can be used by specified users to achieve specified **goals** with effectiveness, efficiency, and satisfaction in a context that is specified by us*

This implies that to achieve the goal **better health outcomes for chronic patients and ergo, healthcare systems resources optimization**, mHealth apps must be designed with the support of human-centred (HCD) and user-centred (UCD)

design approaches. Overall both a HCD and UCD methods guarantee continuous user involvement along the complete design process to achieve a clear understanding of the user needs and facilitate the development of a tool which serves the most beneficial outcome in the most effective way. While the HCD perspective considers the general *human* psychology to achieve a design solution applicable for humans, the UCD focus on a specific solution for the pains and needs of a target group, *user*. Overall, both approaches use the same methods and thus, the terms are used interchangeably in literature [29] and, thus, in this thesis.

These approaches focus on incorporating users' perspective into the app development in an iterative process enabling increased productivity, reduced errors and improved acceptance. Once identified the suitability of HCD and UCD strategies, the process should be performed in four steps illustrated in Figure 2.3. Maguire [29] describes briefly this approach and provides guidelines to different design situations.

This first step is all about researching the users' behaviours, problems, and goals as well as how they might interact with the app. It usually involves approaches as literature review, population surveys, interviews, diary keeping to record user behaviour and task analysis. It is followed by the step that focus on specifying the requirements that are beneficial for both the users and the organisation, and find metrics to measure what success looks like to them. Focus groups, individual or group workshops, user personas and user tasks maps to engage the different stakeholders are carried out in this phase. Step three is designing mock-ups and user flows, testing out different user interface (UI) elements, as well as determining effective information architecture to design a product that solves users' pains. For producing design solutions brainstorming, storyboards, affinity diagrams, card sorting as well as paper or software prototyping are recommended at this stage. Finally, the usability testing with actual users to assess the effectiveness of preliminary designs, and determine if the solution meets the requirements and what needs improvement can be conducted. This process might be iterated as many times as need and where appropriate.

More recently, to further expedite the design process and improve UX, Jeff Gothelf [30] proposed a game changing approach to focus on outcomes instead of design requirements, know as Lean UX. This is achieved through design sprints in a fast feedback loop **build-measure-learn** where *low fidelity* prototypes are created to be shared with users and promote large number of ideas which are then selected and further developed in high-fidelity prototypes.

In sum, the use of HCD and UCD will ensure that the resulting product enables an adequate relationship between the patient, technology and health care organizations with the focus on the end-user.

To tackle the challenges of the current health system in Azores, the target of this thesis is to investigate and develop a mHealth app with focus on the chronic patient population in the RAA using a HCD/UCD approach. As an ubiquitous tool, this mHealth app supports both patients and healthcare professionals. It can be used daily for disease management but also to collect insights of the different chronic conditions that can be leveraged to improve therapeutic outcomes and thus, lead to the optimization of healthcare system resources.

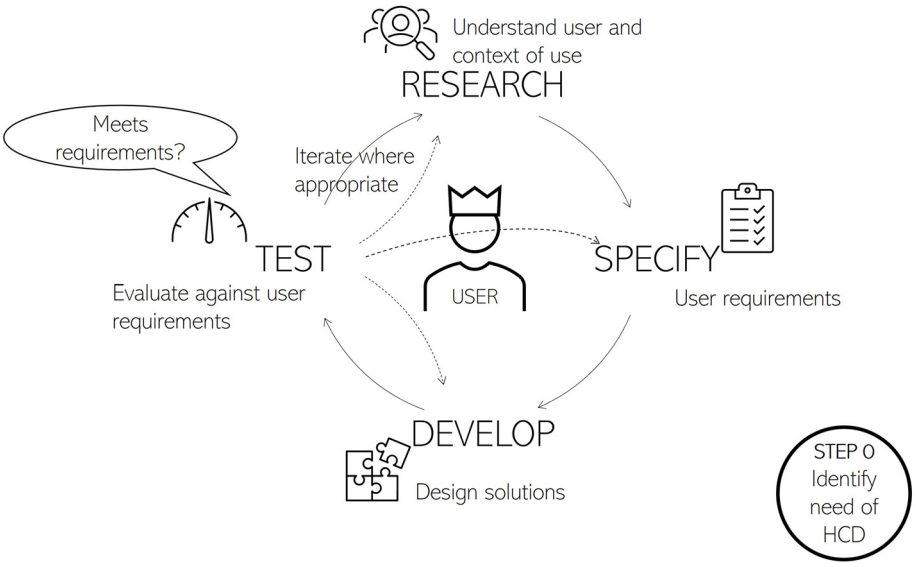

Figure 2.3: The four steps of the HCD process. Compiled by author - adapted from ISO 9241-210:2019.

CHAPTER 3

Investigative methods

This chapter focuses on describing how the first two phases of the iterative HCD approach as per Maguire [29], *RESEARCH* context of use and *SPECIFY* requirements, were performed. The methods used consisted in developing and disseminating a questionnaire within the concerned population to understand the characteristics of chronic patients in the RAA and their specific needs as well as a comprehensive literature review of existing mHealth apps. The motivation for this approach is routed both on the literature review on mHealth tools for chronic patients as well as the research objectives for this thesis.

Following Macguire [29] guidelines, *surveys* are considered as an optimal method to understand and specify the context of use in diverse and disperse populations like the RAA population with chronic diseases. Additionally, there is evidence that compared with face-to-face interviews, with non-face-to-face - like online surveys - respondents are more likely to report health-related events. Overall, online surveys offer several other advantages, namely, the elimination of any bias caused by the appearance of the interviewer or patients feeling pressured to give acceptable responses to elicit positive reactions, lower costs related to the transfers of the interviewer or the person interviewed, lower administrative costs and thus, to reach a larger population sample [31].

While, the *survey* helped to answer the sub-research questions **SRQ1** and **SRQ2** and helped to define the goals for the next iteration. The *existing system analysis* enabled to clarify which functions should be prioritized, set objectives and highlight existing usability problems.

3.1 Questionnaire development

The survey was created using the recommendations from Nielsen for online surveys [32]. Therefore the survey was kept short with questions easy to understand, the objective of the survey was explained at the start and each section of the survey contains a brief explanatory introduction. Furthermore, the survey used mostly closed-ended questions for a statistical result, but a few open-ended were used to collect participants' own conditions and knowledge.

The full-set of 56 questions are classified in 6 sections summarised in Table 3.1. The questionnaire was pretested with a small sample of volunteers from the University

of Azores - staff and students, and took about 5-10 min to respond.

Table 3.1: Sections and references of the set of questions in the survey distributed across the RAA population.

Section	# Quest.	Metrics	Reference
Epidemiologic	11	Qualitative and Quantitative	Demographic questions + Health Days [33]
Medication Adherence	10	Qualitative	Morisky Medication Adherence Scale - 8 (MMAS8) [34] + 2 compiled by author on disease self-management
HL and NPs	21	Qualitative	Adapted from Health Literacy Questionnaire (HLQ) [35] and Health Literacy Survey-EU [23] + 3 compiled by author
Mental Health	12	Qualitative	General Health Questionnaire (GHQ12) [36]
App interest	2	Qualitative	Compiled by author

The primary outcome measures are all self-reported and briefly explained below:

- The **demographic and epidemiologic** data as island of residence, age, genre, weight and height to calculate body mass index (BMI);

- The **health status and health-related quality of life (HRQOL)** are assessed using the self-rated Healthy Days measures developed in 1990s by the Centers for Disease Control and Prevention (CDC) to identify unmet health needs [33]. It consists on a 4-item assessment tool on general health and recent days of physical, mental health and activity limitation. The summary index is known as *unhealthy days*. It is calculated adding together the 2nd and 3rd question with a logical maximum of 30 days. The self-perceptions of patients about their health serve as proxy measures for both health outcomes as well as a prediction of future burden on the healthcare system, as people generally seek care only when feeling unhealthy.

Additionally, subjects are asked about any long-term mental or physical illnesses, defined as chronic illness - illnesses that have lasted or are expected to last for at least 12 months;

- **Morisky Medication Adherence Scale - 8 (MMAS8)** this scale was initially developed to assess compliance in patients with chronic arterial hypertension but it is today used in a variety of patient populations [34], [37]. It is a validated assessment tool to measure non-adherence through short behavioural questions constructed to

avoid "yes-saying" bias commonly seen with chronic care patients. Patients are asked to give yes/no answer in how they fail to take a prescribed medication due to forgetfulness, carelessness, stopping the drug when they feel better or stopping treatment because they believe it makes them feel worse. Only the eighth question is assessed on 5-point Likert scale from "never/rarely" (1) to "all the time" (0). In case of an answer that reflects an adherence issue, a score of 0 is attributed. The total score by adding all eight individual questions and ranges from 0 (bad adherence) to 8 (good adherence). Cut-off values for categorizing respondents' adherence rate as high (8 points), medium (6-7 points) or low (<6 points) were chosen based on Janezic *et al.* [38]. This metric was only included in the survey if respondents self-reported as chronic ill.

- To assess **Health Literacy (HL)**, a section of 18 questions constructed adapting two validated assessment tools: the European health literacy survey (HLS-EU) [23] and the Australian Health Literacy Questionnaire (HLQ) [35] and supplemented with three questions on **natural products literacy** compiled by the author was used. Health literacy is a multidimensional concept introduced in the 1970s of key importance in public and healthcare assessment. In the referenced surveys it is considered as a construct of up to 12 dimensions including the *knowledge, motivation and competencies of accessing, understanding, appraising and applying health-related information within the healthcare, disease prevention and health promotion setting.* In the survey 9 domains were considered. The domains included and their respective statements and questions contemplated are summarised in Table 3.2.

Table 3.2: Health Literacy domains and related statements included in the survey adapted from HLQ [23] and HLS-EU [35].

Domains *Statements and questions*
1. Feeling understood and supported by healthcare providers
I feel understood and supported by my doctor.
2. Having sufficient information to manage my health
I consider I have enough information/knowledge to maintain my health
3. Actively managing my health
I am the one who manages my own health
I can follow my doctor's instructions for managing my health
Do you make plans for healthy practices (diet, exercise, etc.) to ensure you do what is necessary to maintain your well-being?
Do you follow those health plans you make for yourself?
4. Social support for health
I have social support (family, friends, acquaintances) for managing my health
5. Appraisal of health information
When I receive new health information, I will confirm its accuracy
I compare health information from different sources and decide what is best for me
I ask my doctor about the quality of the health information I find
6. Ability to actively engage with healthcare providers
I am able to discuss my health problems with my doctor
7. Navigating the healthcare system
In case of need, I know how to find the health professional I need
I can access the care of the doctor or other health professional I need
I know what healthcare I am entitled to
8. Ability to find good health information
I easily find information about health problems
9. Understand health information well enough to know what to do
I understand my doctor's instructions for managing my health
I understand the information that comes with the medications and/or medical equipment I use
I feel able to understand the health information I receive/find.

The final score that measures the health literacy is computed with 3-Likert-type responses ranging between *"Never", "Sometimes" and "Always"*. Each item is worded in such a way that it reflects the easiness with which the patient deals with the different HL dimensions. The items are rated on a bimodal scale *"Never", "Sometimes"* with the points being 0 in case of an answer that reflects a health literacy difficulty and a score of 1 if not *"Always"*. The total score is computed by adding all 18 individual questions and resulting on a four-level index were 'inadequate' (0–9), 'problematic' (>9-12), 'sufficient' (>12–15) and 'excellent' (>15–18) health literacy inspired in the

rationale in Sørensen *et al.*. Also vulnerable groups were detected by combining the 'inadequate' and 'problematic' levels to a single level, called 'limited health literacy' (0–12)[39].

- To analyse the **Mental Health** status, the 12-item General Health Questionnaire (GHQ-12) was translated and administered. Originally developed in the 1970s consisting of 60 items, this validated and extensively used screening questionnaire aimed at detecting psychotic psychiatric disorders. Thereafter, a brief and more attractive version was designed to establish a more general measure of mental well-being [36] where two areas are targeted - incapacity to perform normal activities and emergence of distress. GHQ-12 consists of 12 items and presents four options for each positive and negative item. In the 6 positive items, the options consisted in "Better than usual", "Same as usual", "Worse than usual" and "Much worse than usual". Whereas, for the 6 negative items, the options presented are "Not at all", "Less than usual", "Same as usual" and "More than usual". Both scored as 0, 1, 2 and 3, respectively. According to Pilar Sánchez-López and Dresch [40], the most realistic type of score for this assessment tool is a 4-point Likert-type scale (from 0 to 3) as it prevents results with large skewness and kurtosis. Thus, the score ranges from 0 to 36. Higher scores indicates poor mental health condition. In Goldberg *et al.* it is determined that the mean GHQ score for the whole population of respondents provides a rough guide to the best cut-off threshold [41].

- Finally, the **interest in a mHealth tool across the RAA population** was inferred from raising two questions compiled by the author.

- *Would you find it useful to have access to a mobile application (App) that allows you to minimize the day-to-day challenges linked to your chronic disease?*

- *Would you be interested in participating and contributing to the improvement of this application in a test session?*

3.2 Participants and Data collection

The study was conducted in the Azorean archipelago. Situated about 1,400 km west of Lisbon, and about 1,930 km south-east of Newfoundland, Canada, the Autonomous Region of the Azores (RAA) is an archipelago of 9 volcanic islands with a total population size of 241,763 inhabitants as per 2018 census [42]. Most of the population is living in São Miguel and in the island of Terceira, 54% and 23% , respectively. Followed by Faial and Pico both with 6%, São Jorge 4% and Corvo, Flores, Graciosa and Santa Maria each with less than 2%.

The criteria for population recruitment were: 18–70 years of age and a diagnosis of chronic disease. The sample was randomly selected by general practitioners and nurses and other health professional staff in each primary healthcare centre (Unidade de Saúde da Ilha - USI) or distributed via the network of the following chronic diseases' associations in Azores:

- Associação Portuguesa Insuficientes Renais (APIR) - Açores
- Associação de Doentes de Dor Crónica dos Açores (ADDCA)
- Associação Alzheimer Açores (ALZA)
- Associação Atlântica de Apoio ao Doente Machado-Joseph (AAADMJ)

3.2.1 Data collection

Each participant was randomly contacted by a health professional staff from primary healthcare centres in the 9 islands between January 2021 and September 2021, which were contacted by email and by phone calls a maximum of 6 times before being considered unreachable or by email and/or Facebook by the different regional associations. Participants received an informative pamphlet, Facebook post or email with the link to the website where the online survey was available. See webpage in Figure 3.1. Social media posts and paper form examples in Figure 3.2.

Google forms was used to create the survey and collect data. The survey can be found in Appendix E (only in Portuguese).

Figure 3.1: Website with link to the questionnaire was available *www.omeubemestar.pt.*

Figure 3.2: Survey dissemination for recruiting respondents. Digital formats: (a) Pamphlet and (b) Facebook post designed;Paper format: (c) Pamphlet and (d) flyer distributed at USI Corvo .

Ethical concerns The study has been designed following the principles of the Declaration of Helsinki [43]. No identifying data were recorded in this study, thus patient confidentiality was maintained. Data was collected using an anonymised electronic database.

The protocol has been approved by the Ethics Committee of the University of Azores. See Appendix A. The Regional Directorate of Health (DRS) also acknowledged the relevance of this study giving its support by disseminating the survey across all USIs via email (Appendix B).

Besides the Ethics Committee of the University of Azores' approval and the support of DRS, in four - Faial, Pico, São Miguel and Terceira - of the nine islands, the approval of the ethics committee of the main USI was required through the submission of extensive documentation, including:

- Submission form;
- CVs of the researchers;
- Statement of responsibility;
- Declaration of conflict of interest;
- Project introduction and plan;
- Informed consent form;
- Internal letter for the Administration president;
- Internal letter for the Ethics Committee president

An example of the documentation required and submitted for approval is given in Appendix C. The project plan and researchers CVs are excluded from the appendices to avoid redundancies. The approvals from each USI are available Appendix D.

Additionally, a consent paragraph was included at the start of the questionnaire to inform respondents on data handling and protection.

3.3 Statistical analysis

Statistical analyses were performed using R studio, version 4.0.4 (2021-02-15), a platform for statistical computing and graphics [44].

Continuous variables, as each section scores, were expressed as mean+-standard deviation (SD) and categorical variables as frequencies and percentages.

3.4 App Concept and Design Research

In parallel with the population survey, to understand users, the context of use and user requirements, a thorough related literature review was performed to further *SPECIFY* potential user requirements and *DEVELOP* possible design solutions as per Maguire guidelines [29].

Several smartphone applications (apps) have been developed and are commercially available for chronic ill patients. Alongside with a scientific literature review, a systematic Google play search was performed and combined to understand the most relevant features and design characteristics for improvement of well-being while ensuring user engagement in chronic patients.

CHAPTER 4

Development of a mHealth tool

In this chapter the baselines with which "Bem Me Quero (BMQ) - App" , was conceptualized, designed and evaluated are further described.

The methods used to perform the two last phases - *DEVELOP* design solutions and *TEST* against user requirements - of the iterative HCD approaches are presented.

According to Maguire [29], *brainstorming* sessions, workshops with *focus groups* and *software prototyping* are effective methods to assist in producing design solutions. While the first, aims at bringing together users representatives and experts to inspire creativity in the early stage of the design process, the latter gives users a more realistic experience of the potential design.

The focus rested on the end-user by involving them during the entire design process.

4.1 User involvement and data analysis

Adopting HCD approaches implies the collection of user inputs and subsequent analysis. The workshops involved both chronic patients and practitioners recruited through regional chronic disease associations via emails, phone calls and social media.
The number of participants was kept low, due to the susceptibility of the topic, as defended by Tynan *et al.* [45]. It varied between 2 to 4 both female and male within the age span of 30-65, in line with Nielsen *et al.* recommendations [46]. According to Markman [47] it is also important that there is a common ground between the participants *i.e.* they all suffered from chronic diseases. Although, the BMQ app was designed focused on the patient, the practitioners play a critical role in giving guidelines for effective health-related communication and features selection [6]. They still have to be considered as collateral users, since they would use the application in cooperation with patients.

The consent for collection of data was verbally given during the workshops. All transcripts were anonymised.

4.2 App Concept and Design Definition

To further delineate the app concept and design solutions, a session with end-users and healthcare providers was conducted at the early stage of the designing process. Focus groups are preferable to individual interviews due to their benefits in time-saving and valuable outputs derived from participants interaction [45]. The focus group was conducted based on the principles from literature [47], [48]. This includes set a time limit between 15-60 minutes for the participants' feedback, begin with a target problem, refrain from judgment and using participatory tools, such as word clouds and rating exercises.

The interactive design process kickstarted with an experiment with low fidelity (low-fi) prototypes. Low-fi prototypes are static concepts not close to the final product. The classification of the prototype fidelity is given by the proximity to the final product. The initial investment in low-fi prototypes is minimal but gives valuable inputs to validate user requirements [49]. The low-fi shared focused on features, to get raw inputs on relevant choices from the focus group and adapt the original idea in the right direction.

4.2.1 Tools

The focus group workshop was held using Zoom. Powerpoint was used to present and share low-fi prototypes. Mentimeter was used as a tool for sharing ideas as well as for rating selected features. Zoom was used to record participants' inputs after consent given.

4.2.2 Participants

Homogeneous - all chronic patients - but contrasting groups - different chronic diseases - were recruited through emails (Appendix F) and phone calls with associations to discuss requirements.

In the workshop, 2 of the 4 participants suffered from chronic kidney disease while other 2 from chronic pain. One of the chronic pain patients was representing simultaneously practitioners and patients.

4.2.3 Moderator

The role of moderator was taken by the author of this thesis.

4.3 App Design Evaluation

To assess the app design against user requirements on engagement, functionality, usability, privacy and security and clinical relevance, a walk-through method was

chosen to challenge the high-fidelity prototype with potential users. In this process, the user goes step-by-step through the system and reactions are recorded [29]. This process can conjointly help to validate the application structure and understand how the application will used by users uncovering potential users' struggles and design inconsistencies. It is considered as an effective way to test BMQ app in terms of usability.

The high-fi prototype was designed by the author of the thesis derived from questionnaires outputs, review of previous work and the initial outcomes from the focus group workshop. It was designed in line with Maguire recommended methods: *brainstorming* and *design guidelines*. The *brainstorming* was performed between the author and the supervisors for idea generation. Apple human interface design guidelines for iOS were used to ensure the use of good practices and design consistency [50].

According to Nielsen *et al.* [46] the tasks the users are asked to perform during the walk-through process should also be kept simple, to minimize the cognitive load and the prototype tested should be functional enough for the users to understand and get acquainted with a more realistic experience.

4.3.1 Tools

The entire prototype was developed in Figma and an Android (Google Nexus 5X) device was used as the simulation environment. The walk-through meeting was held online via Zoom. The app was shared with the participants on Figma. Zoom was also used to record users' inputs after consent given.

4.3.2 Participants

In this iteration, one healthcare provider and one patient were involved. They were recruited through phone calls with associations. Both participants were chronic pain patients and had participated in the initial workshop.

Other chronic disease patients were not available this time.

4.3.3 Facilitator

All user involvement were facilitated by the author of the thesis.

CHAPTER 5

Results

This chapter summarizes the results of the investigative methods (Chapter 3) and user inputs from the two workshops for the design of the BMQ App (Chapter 4).

5.1 Data-driven insights

In the following sections, the results of the qualitative data collected by means of the questionnaire (Appendix E) and the literature review are disclosed.

5.1.1 Questionnaire results

A total of 36 responses were received in this study after removing duplicates from the 9 main USIs and 4 chronic disease's associations invited to participate in the questionnaire. The descriptive findings are summarised in Tables 5.1 to 5.3.

Chronic disease was a dichotomous question (yes/no) and 11 respondents did not self-reported as suffering from chronic disease(s). Yet, 6 were included in the study as chronic patients due to a calculated Body Mass Index (BMI) higher than 25 kg/m^2. Thus, in total 31 responses met the criteria and were considered in this study. See Table 5.1.

In total 29% *(n=9)* of the respondents lived in São Miguel, 19% *(n=6)* in Corvo, 16% in Santa Maria, 13% in Terceira, 10% in São Jorge, and the remaining 12% from Faial, Flores and Pico. The USI Graciosa was contacted more than 6 times. Despite the secretariat administrative council having declared to have shared the information within the staff no response was received, most likely due to organisational changes in the staff and failure in transfer of tasks.

The study sample age ranged from 25 to 71 with an average of 48.9 and a standard deviation (SD) of 12.5. Gender-wise 52% of the respondents were male while 48% were female. The BMI ranged from 18 to 44 kg/m^2 with an average 28.9 (SD=5.8). Overweight status was defined by a BMI between 25.0 and 29.9 kg/m^2 and obesity $\geq$ 30 kg/m^2. In total 77% of the participants reported BMIs above the normal values.

Respondents self-reported a wide chronic health related traits and outcomes: 20% *(n=5)* confirmed chronic kidney disease, 16% *(n=4)* self-reported chronic pain (including migraine and back-pain), 12% *(n=3)* had cardiovascular diseases (hypertension and coronary artery disease), 12% *(n=3)* suffered from a genetic disease. Other conditions self-reported by one participant were: arthritis, chronic prostatitis, depression, diabetes, hypothyroidism, obesity, Parkinson's disease, psoriasis, rheumatic disease and ulcerative colitis. See Table 5.1.

Table 5.1: Epidemiologics of the RAA population sample *(n=31)*.

	Mean (SD)	Frequency (%)	Range
Island residence			
Corvo		6 (19)	
Faial		2 (6)	
Flores		1 (3)	
Graciosa		0 (0)	
Pico		1 (3)	
Santa Maria		5 (16)	
São Jorge		3 (10)	
São Miguel		9 (29)	
Terceira		4 (13)	
Age (years)	**48.9 (12.5)**		25-71
25-35		7 (23)	
36-45		5 (16)	
46-55		8 (26)	
56-65		9 (29)	
65-71		2 (6)	
Gender			
Female		15 (48)	
Male		16 (52)	
Body Mass Index (*BMI*)	**28.9 (5.8)**		18-44
Normal (18.5-24.9 kg/m^2)		7 (23)	
Overweight (25.0-29.9 kg/m^2)		11 (35)	
Obese ($\geq$ 30kg/m^2)		13 (42)	
Chronic disease type	(self-reported *(n=25)*)		
Arthritis		1 (4)	
Chronic Kidney D.		5 (20)	
Cardiovascular D.		3 (12)	
Chronic Pain		4 (16)	
Chronic Prostatitis		1 (4)	
Genetic D.		3 (12)	
Depression		1 (4)	
Diabetes		1 (4)	
Hypothyroidism		1 (4)	
Obesity		1 (4)	
Parkinson's D.		1 (4)	
Psoriasis		1 (4)	
Rheumatic D.		1 (4)	
Ulcerative Colitis		1 (4)	

The health status was self-reported as 'Normal' by 62% of the respondents and as 'Good' on a equal frequency as 'Bad '(19%). While male and female self-percevied their health status in similar ratios for 'Normal' and 'Good', the status 'Bad' was given mostly by female. Only one man qualified his health status as 'Bad'. The average number of unhealthy days reported was 8.9 (SD=10.6) ranging broadly from 0 to 30 days. See Table 5.2.

Overall across the participants that self-reported as chronic patients, 36% (n=9) presented *low adherence* scores to the prescribed medication with a Morisky Medication Adherence Scale (MMAS-8) score < 6 points and 20% (n=5) were considered *moderately adherent*. *High adherence* was observed in 44% (n=11). See Table 5.2.

With regard to the Natural Products (NP) literacy, although 90% of the respondents expressed that *they believe that NPs can contribute for their well-being*, 39% reported to never use them. The most referred examples of NPs used *'frequently'* or *'sometimes'* by 61% of the inquired patients are illustrated in Figure 5.1. Some of the participants attested to use more than one type of natural product. Almost half (47%) of the respondents reported to use teas and tisanes and 16% mentioned medicinal plants, as Aloe Vera and Valerian. Functional foods are defined as nutrient-rich foods that are related to either health promotion or disease prevention [51]. Examples like red rice and linseed were cited by 11% of the survey participants. Nutraceuticals are pharmaceutical alternatives derived from food sources that are prepared to use in management of chronic diseases [52], such as cranberries and omega 3 in capsules, cod liver oil and chondroitin and glucosamine, indicated by 32%.

Figure 5.1: Distribution of natural products used by chronic patients' sample.

Table 5.2: Health related scores and App Interest of the RAA population sample *(n=31)*.

	Mean (SD)	Frequency (%)	Range
Health-related quality of life (*HRQOL*)			
Self-reported *Health Status*			
Good		6 (19)	
Normal		19 (62)	
Bad		6 (19)	
Mental unhealthy days	**5.3 (8.3)**		0-30
Physical unhealthy	**5.5 (8.4)**		0-30
Unhealthy days	**8.9 (10.6)**		0-30
Medical Adherence (*MMAS-8 score*)			
High adherence (8pt)		11 (44)	
Medium adherence (6-7pt)		5 (20)	
Low adherence (<6pt)		9 (36)	
Natural Products (NP) Literacy			
Appraisal for NP			
Yes		10 (32)	
Depends on the products		18 (58)	
No		3 (10)	
Use of NP			
Frequently		1 (3)	
Sometimes		18 (58)	
No		12 (39)	
Mental Health Status (*GHQ-12 score*)	**12.5 (4.8)**		6-23
>mean		15 (47)	
<mean		17 (53)	
App interest			
Appraisal for mHealth App		25 (80)	
Intention in testing workshop		13 (42)	

For the study sample (Table 5.2), the total *GHQ-12* scores ranged between 6 and 23 with the mean score 12.5 and standard deviation 4.8; 47% of participants had a total GHQ-12 score above the mean indicating poor mental health and 53% below.

The two last items (in Table 5.2) of the questionnaire enquired the respondents on their interest on a mHealth app to support in their chronic illness-related daily challenges as well as on their interest to contribute to the development and improvement of such a tool. The answer to the first question was clear, 80% of the respondents communicated their interest in an mHealth app to help minimizing the burden of

their chronic condition. Still, only 42% expressed their interest in contributing in its development and enhancement.

The distribution of the HLS score - see Table 5.3 - revealed that most of participants had "inadequate" (39%) and "problematic" (45%) health literacy levels. Only 16% of the sample were found to have "sufficient" (10%) or "high" (6%) levels. The domains in which participants reported to be more vulnerable where in *Actively managing my health, Social support for health, Appraisal of health information, Navigating the healthcare system and Ability to find good health information*, for these domains the score was lower than 1 for more than 35% of the respondents. The most of respondents (>80%) revealed to *feel understood and supported by healthcare providers, have sufficient information from healthcare providers to manage my health, be able actively engage with healthcare providers and understand health information well enough to know what to do.*

Table 5.3: Health literacy levels of the RAA population sample *(n=31)*.

Health Literacy score (***HLS***)	Frequency (%)
Total	
Excellent($\geq$ 16)	2 (6)
Sufficient(>12-15)	3 (10)
Problematic(>9-12)	14 (45)
Inadequate(0-9)	12 (39)
Domain Score=1 in at least one statement/question	
Feeling understood and supported by healthcare providers	25 (80)
Having sufficient information to manage my health	26 (83)
Actively managing my health	17 (55)
Social support for health	15 (48)
Appraisal of health information	12 (39)
Ability to actively engage with healthcare providers	28 (90)
Navigating the healthcare system	20 (65)
Ability to find good health information	20 (65)
Understand health information well enough to know what to do	25 (80)

The key findings of the population sample questionnaire are:

- In average, the respondents self-reported to experience 8.9 mental or physical unhealthy days during a month
- 56% of the respondents presented low adherence to the prescribed medication
- Although 90% of the participants believe in the potential of natural products to enhance their well-being, 39% never use them

- HLQ scores uncovered that 84% of the respondents have limited health literacy levels. The domains where the literacy levels are more problematic are related with self-management, social support as well as ability to find good information.
- In total, 80% of the survey partakers revealed their interest in having access to a mHealth app that could help attenuate the daily challenges related with their chronic illness.

All these findings give the basis for the subsequent design phases by elucidating on the context of use and user needs.

5.1.2 App Concept Research

From the combination of 18 scientific articles focused on the development of mobile apps for chronic conditions and 33 commercially available apps for these conditions with at least 100 downloads, it was concluded that the most used features of mHealth apps have been: tracking symptoms, health data export as well as motivational feedback and advice to inspire healthy habits and adherence to medication.

Figure 5.2 illustrates which features are more relevant for 15 different chronic conditions in both commercial apps and scientific articles (highlighted in light grey). Most apps offers more than one feature. The order of relevance is given from top to bottom, where the most used features for a specific condition appear on top of the chart and the less used at the bottom. Some apps are multi-conditions, in the sense they include more than one chronic condition, for example 4 apps were developed for patients suffering for at least one or all of the following conditions: Chronic Obstructive Pulmonary Disease, Diabetes, Hypertension and Obesity [53]–[56]. Other apps are more simplistic, focusing only on one condition and offering only one feature [57]–[61]. For example, the App developed for Parkinson's Disease provides exclusively psychotherapeutic exercises to its users [62].

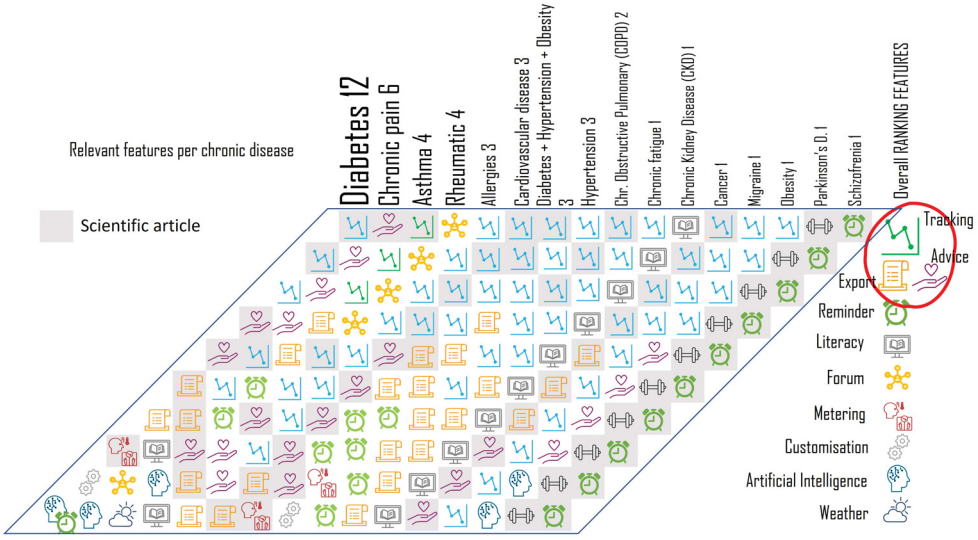

Figure 5.2: Most used features in apps developed for chronic patients.

In total, 11 different features are considered relevant for the different chronic illnesses. In alphabetic order: Advice, Artificial Intelligence (AI) to transform collected health data into effective self-management actions and prevent adverse effects, Customization of key features - like treatments, Forum, Export, Literacy (health), Metering, Reminders, Therapeutical exercises - based on medical guidelines and best practices, Tracking of symptoms - as evidence for clinical outcomes improvement and weather. On the rightmost side of the illustration the top 10 features are ranked from top to bottom. See features definitions and respective references in Table 5.4.

The most popular features revealed to be **Tracking** and **Export** of health related variables as well as **Advice**. Followed by Reminders, Literacy, Forum, Metering of automatically sensed data, Customisation, AI and finally, weather.

With regards to design characteristics, literature points that an **user-friendly design - simple, self-explanatory, and visually appealing as well as low time consuming** app is recommendable. Individualized elements - **customization** that may include personalized reminders and alerts tailored to a user's specific needs and medical conditions are also encouraged [1], [63].

Together with the key findings of the questionnaire, this literature review provides evidences to the most promising features to be considered in the development of an App for chronic patients in the RAA.

Table 5.4: Existing system analysis: Overview of literature review and Google play store research.

Feature	Definition	Refs.
Advice	Health-related information is shared via communication with physician or from guideline database	[57]–[61], [64], [65] [66]
Artificial Intelligence	Monitor symptoms and adapt feedback	[67]–[69]
Customization	Customize trackers	[70]–[72]
Forum	Connect with community	[73], [74]
Export	Export data	[54], [57], [59], [60], [64] [65], [67], [71], [72], [77]
Literacy	Literacy based on scientific articles	[75]
Metering	Automatically sensed data monitoring	[76], [77]
Reminders	Any type of reminder/notification	[54], [56], [70], [78] [72], [79]
Tracking	Visualization of tracked data	[54], [77], [80]–[82]
Training	Database of therapeutic exercises	[62]
Weather	Weather forecast for symptom prevention	[71], [81]

5.2 App Development

The results of the workshops with users and practitioners to define and evaluate the concept and design of the Bem Me Quero (BMQ) - app are presented in the following sections.

5.2.1 App Concept and Design Definition

The initial concept of the BMQ app was defined by describing the problem through the characterization of the user context in the research phase. The BMQ app concept and design was then boosted with an interactive ”kickstart experiment” design workshop, as illustrated in Figure 1.1.

An initial validation of the concept of BMQ was implemented by engaging users in the design process. The approach for this method is to keep ideas short and be open to a large number of ideas to be recorded as proposed in [29].

The goals of the implemented methods presented in Chapter 4 are condensed in Table 5.5.

Table 5.5: HCD - Producing design solutions method: "kickstart experiment" workshop. Overview.

Goal	(i) Define target group	(ii) Understand their pains	(iii) Select relevant App features
Methods	Network Research	Focus group	Low-fi prototyping
Participants	None	Patients & Doctor	Patients & Doctor

The discussion agenda was created and tested previously to the workshop (Appendix G *only in Portuguese*).

The workshop was held online on the July, 2nd, 2021 between 6.30pm and 8.30pm (Azores local time, UTC+1) via Zoom.

After sharing simple recommendations for the online interaction, in this session, participants were initially asked to participate in a short general ice breaker. Ice breakers are recommended to improve the atmosphere and effectiveness of online interactions [83]. Additionally, they allow to introduce participants to tools that will be required in posterior interactions during online workshops and test their functionality, in this case, it allowed participants to get comfortable with Mentimeter and to test the sound quality of all participants prior to the main discussion.

Prior to the ice breaker, a short round-table was done.

Subsequently, the focus of the discussion was brought to the project and the main goal of the workshop. An introduction of the main goals of the research project and the preliminary results of the questionnaire were shared with the participants to give context and motivate participants as recommended by Markman [47].

The participants were then asked to add on an interactive whiteboard in Mentimeter which are the main daily concerns related to their health condition. The answers were collected and shared in a word cloud. The word cloud permitted to uncover the most common everyday pains (Figure 5.3) and gave base to subsequent discussion. From the consequential discussion, users' pain were grouped into related categories, resulting the following main concerns:

- **Medication**;
- **Physiological variables** like blood pressure, hydration, kidney condition (see Figure 5.3);
- **Mental and physical impairment** and
- **Social - including work context - acceptance**.

Participants confirmed that although the concerns are specific to each chronic condition. Chronic conditions have in general shared concerns. One of the participants expressed this insight by concluding that:

> *"What matters is that people come together to discuss ideas so that they can be heard. We should appeal to all chronically ill associations at regional level to join together precisely to fight for the needs of their members, in this case patients" (...)*
>
> *I will set a challenge. Next year we will organise a meeting of associations (...) Here is where I think the Carolina's project can help"*

Meaning that the existence of a tool that would enable to have a common voice for chronic patients supported by real data would facilitate the dialogue to bring to the agenda initiatives and policies that generate real well-being improvement for chronically ill patients.

Additionally, on a side note, the participants recognized that the national policies *"leave much to be desired"* with regards to chronically ill patients. They recognized the potential of the Autonomous Region of the Azores as a region to implement innovation in health system related initiates due their population size and, to certain extent, autonomy. In their words: *"here, in Azores, we could be a laboratory to the national context"*.

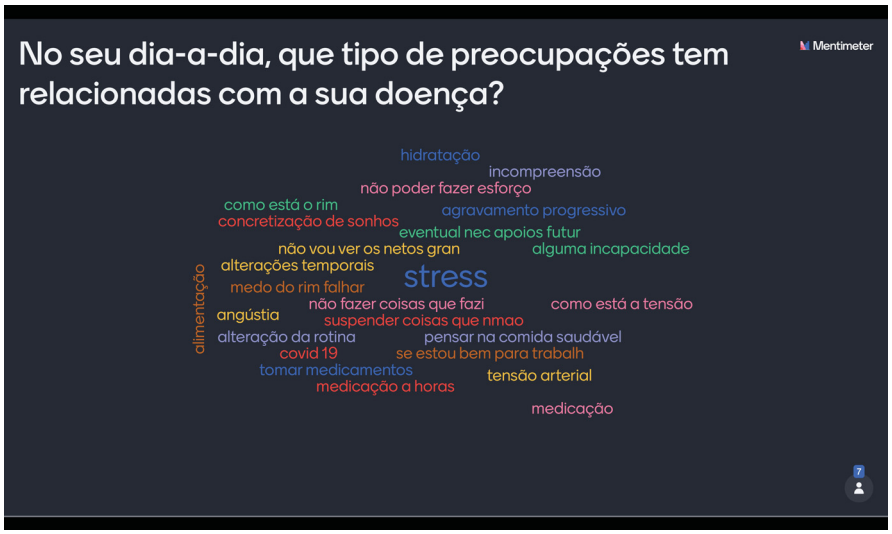

Figure 5.3: Answers to *"What are your main everyday concerns related to your health condition?"*.

With the previous answers in mind, the design ideas illustrated with the low-fidelity (low-fi) prototype were shared. These ideas were inspired in existing apps from the review of prior work and questionnaire results.

When asked which features would be useful to support the daily challenges related to their condition the participants preferences from the selected features were:

Advice (33%), **Forum**(17%), **Reminders**(17%), **Tracking of automatic sensed data**(17%) and **Literacy**(17%). See Figure 5.4.

Figure 5.4: Rating results of selected features.

The advantage of using focus groups permitted to understand that most relevant features are perceived differently by each participants' point of view. Only Advice seemed to be common to more than one participant. This indicates that customization is recommendable when designing apps for chronic patients.

Additionally, ideas were shared to reinforce the importance of improving self-management skills in chronic patients, in the participants' words:

"A large portion of healing begins in the patient"

This kickstart experiment design session defined some of the feature options, that are further investigated qualitatively in the App Design Evaluation.

5.2.2 App Design Definition

Based on the outcomes of the ”kickstart experiment” design workshop, the following initial design of the BMQ - app was created using Figma. Users were not included at this stage as they may lack the necessary knowledge and skills to be involved in the actual design [84].

5.2.2.1 Visual Identity

BMQ - Açores's logo was compiled by the author. The main colour for logo, main screens, etc. is blue. This was chosen, due to the Azorean archipelago main colour and identity ”in the middle of the Atlantic ocean”. The logo is then surrounded by 7 different colours inspired in the 17 sustainable development goals of the United Nations, which includes the shared common goal with this project to ”ensure healthy lives and promote well-being for all at all ages” [85]. BMQ's logo can be seen in Figure 5.5.

Figure 5.5: BMQ's logo.

5.2.2.2 Screens

The concept of BMQ - Açores app consists of four key features: main - overview of the trackers, reminders, literacy and forum (Figure 5.6). These features are visible in all screens of the app have a colour assigned to them, e.g. Reminders is orange to ensure low *learnability* and good *memorability* [86].

The icons used for representing each of the features in the BMQ - Açores app environment are inspired by iOS icons from the Apples guidelines [50] and are adjusted to fit the context of BMQ. The menu of BMQ is a tab bar in the bottom of the screen to allow the user to easily navigate between the four features. It is always present in all main features screens. The following subsections present some of the screens created for each feature.

Figure 5.6: Features of the BMQ - Açores concept. Main (Geral), Reminders (Lembretes), Literacy (Literacia) and Forum.

Figure 5.7: Main Screen - Dashboard.

Main Screen - Dashboard The main screen is a dashboard where an overview of the selected trackers is shown. The user can select to see it on daily or monthly total or averaged values. Furthermore, below the selected trackers, an overview of the medication reminders is given in horizontally scrollable bar. Finally, can jump to the daily literacy item or chose to see the progress of the trackers.

1. This is where the user can see their data from selected trackers, either represented as key metrics or visualized graphically.

2. This medication reminders overview enables the user to track the medication adherence on a daily basis. When the user opens the app, it will be able to see if it has missed any of the prescribed medication given the current time of the day. In case that by the time being one of the prescribed medication has not been checked on the tracking screen by the user when the notification reminder was shown, the drug logo will be coloured in red both on the medication reminder bar and the tracking screen. See notification and tracking screen Figure 5.8.

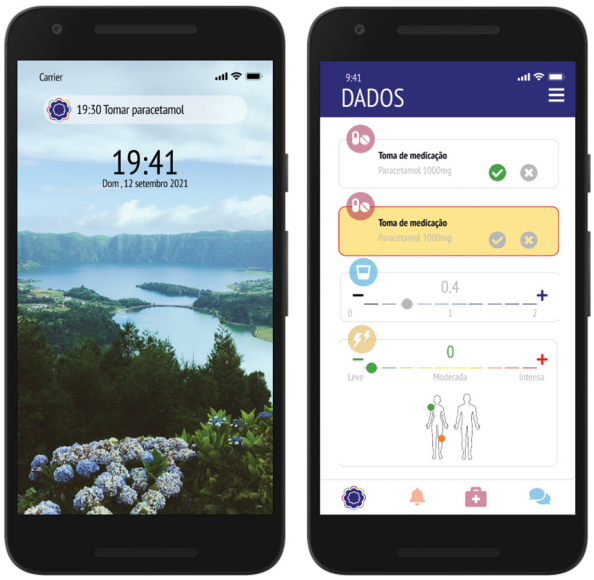

Figure 5.8: Example of notification and medication check screen.

3. If the user selects this section, it will be immediately redirected to the literacy article suggested for the day.

4. This icon directs the user to the graphical interface where users can visualize relationship between trackers in a selected period.

5. This is settings icon which will open the settings bar on the right side of the screen (Figure 5.9). It is available in all feature screens, in the same position.

   This module consist of the profile, account settings such as device and notification setup, data policy, user preferences, an about module including help, and a tutorial and a log out. The profile includes name, email, password and the possibility to delete the profile. The preferences shows the trackers that are automatically suggested by the app depending on the chronic condition(s) selected but also offers the user the possibility to opt in or out of trackers.

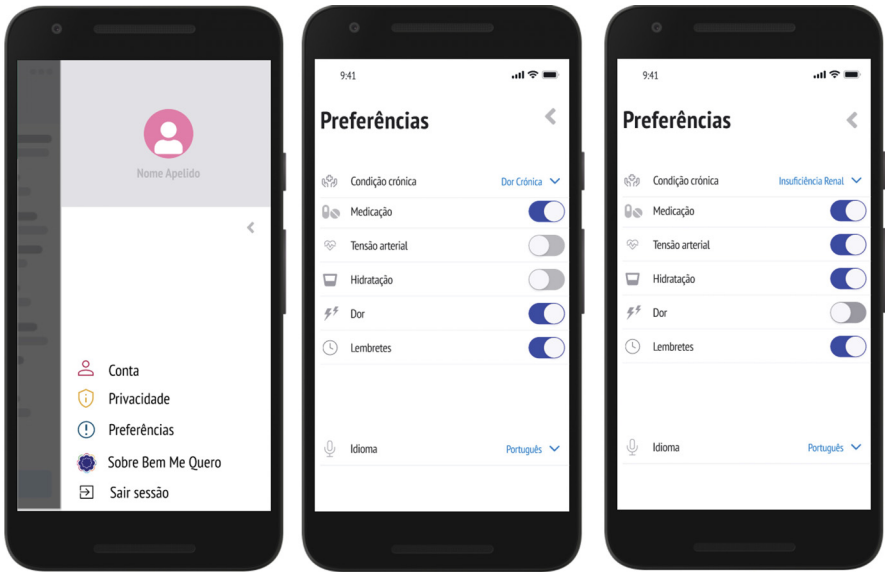

Figure 5.9: Settings and preferences screen. Examples of suggested features for chronic pain and chronic kidney disease.

Tracking and export Within the tracking and export feature, chronic patients will be able to see the data and export the data for user specified trackers and specified period. User have the possibility to have up to three trackers shown simultaneously in one graph. This is where the client can see their tracked history within BMQ - app. Figure 5.10 shows three screens within the feature of tracking and export. The first screen shows the main tracking screen, each of the functionalities inside this screen are described below. The screen in the middle shows the screen for period selection. The third screen is the export, where the period and trackers must be selected to export. To be directed to this screen the users' shall click on the right top icon "Exportar" and there, to create the report it should click on the icon "Gerar PDF".

1. This is where the user can select which trackers to visualize and assess potential interactions between trackers. In this screen example, medication and pain were selected.

2. This is the statistics for the specified period and selected trackers are shown. Under them feedback, goal setting and motivational messages can be shared, as suggested in literature [87].

3. This is the chart area where trackers are displayed. The user can scroll horizontally to see more data.

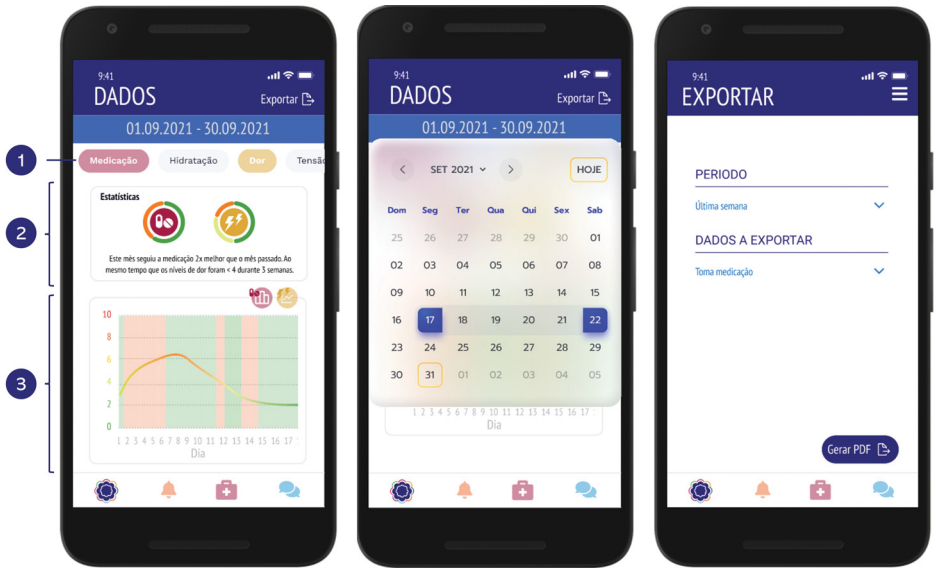

Figure 5.10: Tracking and export screens within BMQ - Açores app environment.

Reminders The reminders feature gives the users an overview of the reminders for today, tomorrow, week and month represented by each of the 4 coloured squares, respectively. Users can also search for a specific reminder in the search bar below. When clicking in one of the squares, the user is directed to the selected period. The middle screen in Figure 5.11 shows an example of the weekly calendar. A specific day can be chosen in the calendar and it will show the user the reminders in the given day. The rightmost screen in the same figure exhibits the types of reminders that users can add to the reminder feature. In this example, the user can add reminders related to medication, appointment, tracker data input and supplements.

Figure 5.11: Reminders screens.

Health literacy The main health literacy screen gives an overview of an adapted Chronic Disease Self-Management program inspired in the evidence-based Stanford's model [31], that the patients should be able to follow when using BMQ - Açores app. This program is focused on increasing the ability of patients with chronic disease to deal with health problems, also known as self-efficacy, which has demonstrated to have positive impact in health status.

This adapted program is common to all chronic diseases. It includes an initial step (00) where chronic patients are introduced to strategies for managing psychological factors such as pain, fatigue, frustration and social stigma. After this foundation, the patient should be educated in terms of appropriate use of prescribed medication (01), followed by advices on sleep and nutrition (02), effective health-related communication on a daily basis but also during medical interaction (03) and finally introduced to decision making strategies. This program can span from few weeks to months depending on users' preferences.

Figure 5.12: Literacy structured program and example of articles shared.

Forum Finally, the feature forum it is a place for users to connect - from treatment experiences to strategies to cope with the long-lasting symptoms related to their condition. Topics can be opened and commented by any user. Figure 5.13 presents the Forum screen with several topics open. These topics are to be identified with tags proposed by app and selected by the user and classified by the app expert into categories. The different items can be selected as favourites by the user.

1. In this section users are able to filter topics by categories.
2. All the topics are displayed with an image related to the topic. Followed by main chosen tag, title of topic and finally category.
3. This icon informs on the number of comments within this topic.
4. If clicked this item is selected as favourite by the user.

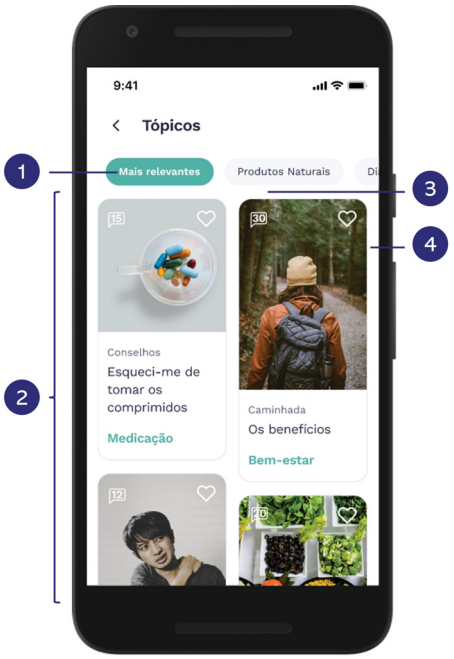

Figure 5.13: Literacy structured program.

5.2.3 App Design Evaluation

Subsequently, a design workshop was held October, 8th, 2021 between 8pm and 9pm via Zoom.

The main goal of this session was to evaluate the app content against users' needs. The sub-goals of the implemented method are condensed in Table 5.6

Table 5.6: HCD - Evaluation design against user requirements method: Walk-through session. Overview.

Goal	**(i) Define trackers to be included**	**(ii) How to share health literacy contents**	**(iii) Evaluate flow and screen interaction**	**(iv) Risk assessment forum feature**
Methods	Walk-through	Walk-through	User journey	Walk-through
Participants	Patient & Doctor	Patient & Doctor	Patient & Doctor	Patient & Doctor
Questions	1 & 2	3	-	4

Since both the participants were present in the prior session, immediately after a short remembrance on the conclusions of the first design session, the high-fi prototype was shared.

Participants were introduced to the Welcome journey for a first-time user. During the walk-through process they agreed that the simple and intuitive design was attractive and valued the welcome questionnaire to build the main screen preference.

Example User Journey - First time user

- When clicking on the icon of the app, a splash screen with the logo is presented to the user. First of all the user is asked to create an account by defining name, email address and password. See Figure 5.14.
- The following screen enquires the user in terms of gender - two icons are presented to be selected on the top right, age, height and weight. Subsequently, the app requests information on chronic condition(s) from a list based on the answer the app makes an initial suggestion on relevant trackers for the specific condition(s). At this moment, the user is given the option to add more trackers if desired. See Figure 5.15.

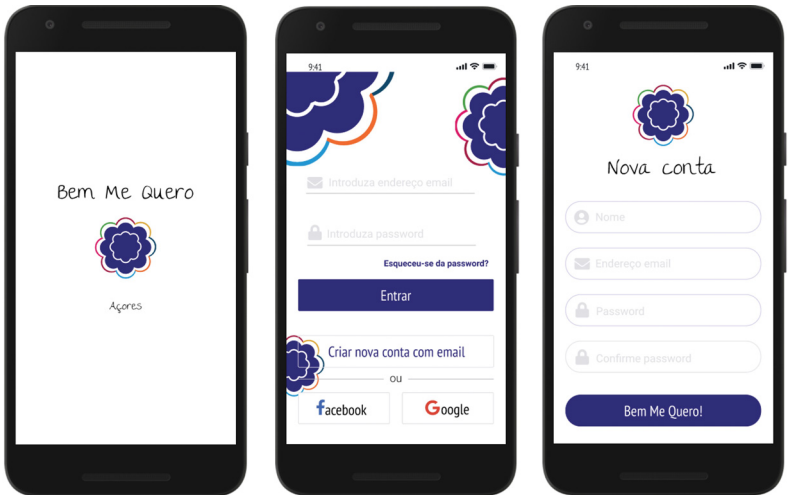

Figure 5.14: Splash Screen and Login.

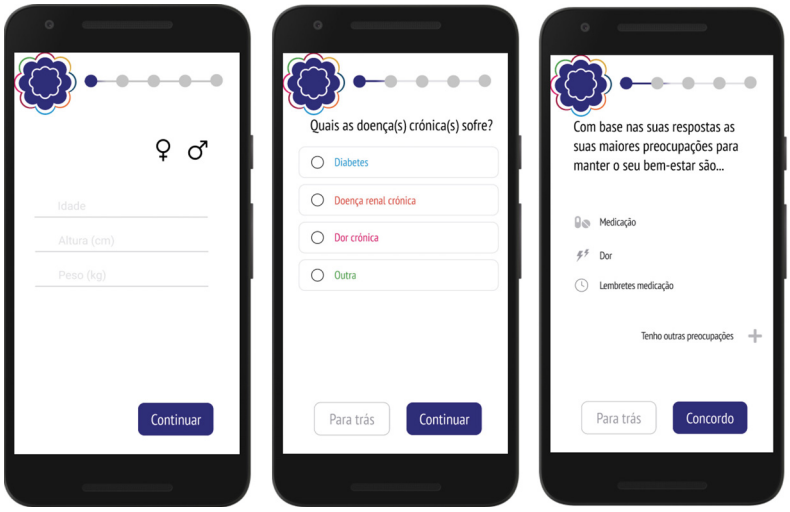

Figure 5.15: Welcome questionnaire for App customization *(continues...)* .

- The app gives feedback to the users to keep user engaged [86]. It informs that the *"process is half completed. Only two questions remain. These questions will help to personalize the app content"*. The following questions are used to personalize the self-management program journey. The user is asked "How is in general you day?". The options given are:"I have very little time for myself",

”I have a lot to do but I safe time to relax” and ”I am usually free and flexible with my time”. This question is used to deduce the time the user intents to spend using the app per day. Finally, the user is asked if she/he relays on other people for health management. See Figure 5.16.

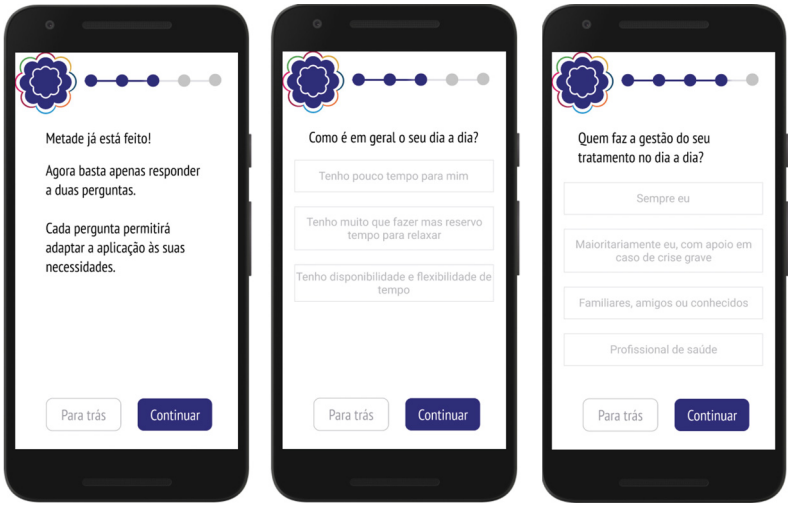

Figure 5.16: Welcome questionnaire for App customization *(continues...)* .

- The last three screen of the first-time user journey are informative. They intend to inform the user on (i) how much time per day is expected to use the app; (ii) what will the app do *” We will share daily articles for habit-strength and improve your well-being. We intend to change your perspective towards your condition. The best part is that it help on your daily life. If not-so-good come along, it is ok. We will learn and do better next time.”* and finally, the main goal of the BMQ - Açores app: *”Our mission is to strengthen your ability to manage your well-being”*. See Figure 5.17.

Figure 5.17: Welcome questionnaire for App customization.

Based on the micro-interactions definition, the user journey was validated by the walk-through process. Flow and screen interaction was difficult to measure since the patients did not get manage to test the prototype on their end due to time constraints.

As the participants went through the features screens of the high-fi BMQ app prototype, they were asked to assess the content in a semi-structured way. The questions are listed below and the participants inputs revealed immediately after:

1. ***How do you consider the selection of trackers?***

   Overall, the participants implied that the selection was pertinent but they identified missing elements. Several other trackers could be consider to fully capture the complexity and diversity of chronic patients. Trackers like mood, sleep, physical activity, nutrition and social interactions were cited.

2. ***Is customization - i.e. choosing which trackers - a valuable feature or it should be standardized?***

   Consensus was that definitely customization should be implemented. At this moment, the patient expressed concerns also with the notifications, when an example of pop-up medication reminder was shared. The patient was concerned with the possiblity of modifying the notification modes according to their preferences.

3. ***Should it be shared randomly on a daily basis or following a specific program - as per Stanford model?***

   When examples self-management tips were shared with the participants. The advantage of including two different perspectives was revealed. While the patient

declared satisfaction with the opportunity to improve health literacy through informative daily articles and tips, the practitioner advocated for sharing it in a structured way.

4. ***Risk assessment of Forum feature. Share the potential format and question if there is a risk of disregarding clinicians recommendation?***

   In the same line of thought than the answer to the previous question, the practitioner proclaimed that the forum feature should be validated by health professionals.

CHAPTER 6

Discussion

This master's project was motivated by the increased number of residents in the Autonomous Region of the Azores (RAA) reporting a poor self-perception of health in the last decade [2]. Ageing of the population and high prevalence of several chronic pathologies could explain this decline. This constitutes an augmented pressure on resources of healthcare systems in Azores [3]. mHealth apps have the potential to support the future of the Azorean healthcare system by delivering healthcare services to chronic patients at any time and reach areas in the Azores where under-served population live [6]–[9]. Yet, the successful adoption of these tools requires involving all stakeholders from the early stages of the design and development of these solutions [28]. Thus, the main research question of this project is:

> **RQ** What is the design of a smartphone-based system that support chronic patients' in their everyday life in Azores?

Three sub-research questions (SRQ) to guide the research work and answer the main RQ were defined. They are discussed in the following subsections.

Managing a chronic condition

> **SRQ1** How do chronic patients in Autonomous Region of the Azores (RAA) manage their condition? What are their main challenges?

The results from the questionnaire disseminated across the chronic population in the RAA demonstrated that only 16% of the respondents have adequate level of health literacy (HL). Compared to the results of the HLS-PT data, the chronic ill population of the RAA is situated below the levels encountered in mainland Portugal [24]. This low HL levels might support the results of the section on medical adherence which revealed that more than half (56%) of chronic patients in RAA struggle with prescribed medication adherence, confirming the results in other populations of chronic patients [20].

It was found that although chronic patients in RAA feel (i) understood and supported by healthcare providers, (ii) have sufficient information from healthcare providers to manage their health, and (iii) feel able to actively to engage with healthcare providers and understand health information well enough to know what to do.

They struggle to (i) actively manage their health, (ii) navigate in the healthcare system, (iii) find social support for health-related complications and (iv) be capable to appraise health-related information.

In agreement with the last Regional Health Survey (InReS) [2], the results of the population survey demonstrated a high prevalence of pre-obesity and obesity in the Azorean population. According to the survey's results 77% of the sample revealed worrisome levels of overweight. Yet, this result is slightly above the results of the InReS in 2014, where obesity was prevalent in 64% of the total population in the Azores. Therefore, the results suggest a link between obesity and chronic disease discussed in literature [88] and imply the importance of encouraging behavioural changes [1], [4].

Half of the respondents revealed worrying levels in the overall psychological well-being, pointing out that physical long-term chronic diseases might impact on the mental health, which has been associated with poor medication adherence [7].

Overall, this work suggests that patients in the Azores are generally satisfied with the healthcare system, but they are not able to manage their health sufficiently.

Literacy levels in natural products

> **SRQ2** What is the current health and natural products literacy level among the RAA population?

It could be inferred from the survey that 90% of the chronic ill sample *"feel that the use of natural products can contribute to their well-being"*. Yet, almost 40% revealed never to use them. Prior studies have found similar results in other populations and associated the uptake of complementary and alternative medicine with a range of socio-economic, demographic and health indicators [89].

The literacy in natural products combined with tracked health status by using a mHealth tool, like the proposed app, could offer new insights to improve health outcomes. This approach could offer opportunities to boost the clinical efficacy and safety of existing drugs as well as catalysing patient-centred solutions as proclaimed Bulaj *et al.* [20].

Therefore, this work considers the inclusion of a app feature that aims at improving regional natural products literacy levels.

App features

> **SRQ3** What design and features are perceived as relevant among chronic patients to increase health related quality of life?

This question was answered with the users' inputs. Based on the results of the survey and research on prior work, several features and designs were presented to patients and practitioners, as end-users. They shared insightful feedback during the workshop and prototype sessions. Both sessions have contributed with relevant suggestions in terms of new or missing elements. The features selected for BMQ - Açores

app had to be useful and engaging for the chronic patients and bring added value to practitioners into gaining new insights on chronic diseases [28].

Based on these considerations, healthcare advice, forum, reminders, tracking of health-related data and improvement of health literacy were selected as key features.

In this way, BMQ-app offers to accommodate self-awareness by presenting tracked data to the user, which could then be shared with the healthcare providers. Additionally, participants stressed the importance of personalization to embrace all chronic disease specificities, so 'what trackers' will be defined by the BMQ's app users.

The importance of healthcare advice available at any time was highly encouraged. An opportunity that was welcomed by the healthcare providers was to deliver health literacy in a structured way. This confirmed the initial idea of integrating in the app a training scheme inspired on Chronic Disease Self-Management Program model developed by a team of researchers at Stanford University [90]. This approach advocates for the central role of patients managing their illness - as also mentioned by participants in the workshops - and it is based on training chronic patients on a highly structured way on self-efficacy - confidence in the ability to manage health-related challenges to improve health behaviours.

The feature forum was suggested and included as a social support for health. This would help overcoming one of the difficulties detected through the survey results on the domain of health literacy.

All-embracing and to answer the main research question, the design of a smartphone-based system to support chronic patients' in their everyday life in Azores should include:

- A feature for health-literacy improvement

  Health literacy levels in the chronic ill population of the Azores was found to be limited in agreement with similar results in other populations [6], [24]. Patients and clinicians during the workshops highlighted their concern on this regard.

  One of the concerns referred by the participants of the workshop was the traceability of medication and physiological variables as hydration, blood pressure and pain levels, etc. See Section 5.2.1. Visual analytical tools of selected trackers were made available in the main screen of BMQ - Açores app to facilitate the patient to better understand their current health status. Furthermore, a possibility to see the progress and find interactions between trackers during a given period is given in a secondary screen (Figure 5.10). Still within this progress screen, short feedback messages can be shared with the patients as motivational triggers for improvement or a positive reward for good progress. Goal setting and real time feedback are encouraged for behavioural change [6], [87]. All this data is exportable so the patient is able to share it.

  Yet, individual differences exist in the relevant health-related variables to be tracked according to the different chronic conditions. Hence, the possibility to chose different trackers is given.

Additionally to the dashboard with trackers, a scrollable bar with the daily medication overview is given to support the patient in following the prescribed medication plan and potentially improve therapeutic outcomes in line with Montes *et al.*[78] and Badawy *et al.*[7].

Furthermore, clinicians referred the importance of providing advice and self-management information in structured way confirming the strategies applied by successful evidence-based programs on self-management of chronic disease [90]. BMQ - Açores app was designed with literacy feature as a support for the educative material to be guide the user towards a better relationship with the chronic disease.

- Reminders

  During the prototype and design sessions as well as according to the survey results, chronic patients in the Azores acknowledged that they struggle with medication adherence in line with Bulaj [20]. The idea of supporting patients with reminders on a smartphone app was positively received. Patients also cited medical appointments and reminder to input data to be tracked in the system as they keep this tracked today in a paper format. This led to the design choice to add a feature where reminders for medication, medical appointments, health-related variables to be tracked and other supplements (Section 5.2.2.2).

- Forum

  One group of patients in the initial workshop mentioned the lack of social support and understanding towards their condition. In BMQ - Açores app a forum is designed to support chronic patients with these challenges (Figure 5.13). Clinicians recommended that the content of this feature should be supervised and validated by healthcare professionals.

Overall, the design of the smartphone-based system should prioritize usability as mentioned in Maguire [29]. During the design of BMQ - Açores well established and successful guidelines for human computer interfaces were followed [50], [86].

6.1 Limitations

This masters' thesis project was developed in close collaboration with regional chronic disease associations.

The iterative approach of the User Centred Design (UCD) process have proven to be extremely valuable giving a lot of inputs from the users and healthcare providers, that would otherwise not have been taken into consideration. This approach enabled to translate design ideas into testable and tangible artefacts more effectively. Yet, all research methods come with trade-offs and limitations.

One limitation of this study is that considering a total population of 241,763 inhabitants, the sample size should have been 384 for statistical significance using a

confidence interval of 95% and a margin error equal to 0.05 [91]. Yet, the response rate was approx. 10%.

Since the only data collected in Faial, Pico, São Miguel and Terceira - which are the island where nearly 90% of the Azorean population lives - was received through the regional associations of different chronic diseases, it is possible that the higher bureaucracy level has jeopardized the data collection in these islands and the overall response rate of this study. In the USIs, the ethics approval took up to 9 months.

In the context of the COVID-19 pandemic, all brainstorm sessions and workshop were held online. Although this format offers convenience and cost-effective way to meet. The outcome of these interactions are less understood and could have introduced communication barriers inherent this impersonal interaction [92] as well as prevented more participants due to technical challenges with the tools used.

Designing for patients Patient involvement is crucial to develop quality of care [93] and effective mHealth tools, as it enhances the usability of these systems [86]. Yet, the involvement of patients and healthcare professionals can be challenging. In the context where this project was developed, the bureaucratic and administrative burden might have hindered the collection of data as well as the engagement of chronic patients in the design process.

This work only managed to include patients and related clinicians of two chronic conditions -chronic pain and chronic kidney disease - in the workshop sessions. Furthermore, the last workshop was a case study with a single user and a clinician which might introduce subjectiveness and compromise the representativeness to the broader chronic population in the RAA. Access to more patients with different perspectives, would speed up obtaining relevant knowledge and results would be more applicable to heterogeneous groups of patients.

6.2 Implications and Future work

This master's thesis project has a number of important implications. First, the results of the survey were useful in further assessing chronic ill population in the Azores. To the best of our knowledge, this is the first study in Azores that comprehensively attempts to assess this population.

Moreover, at the chronic patients' population level, the app can help to connect this population to have a common voice towards the development of more effective regional policies. Apart from becoming more knowledgable on the self-management of their conditions, the healthcare providers will obtain data from their patients, which will allow to potentially improve their practice but also improve therapeutics outcomes.

The participants had other suggestions to the trackers presented in the high-fi BMQ app prototype (see Section 5.2.3). They should be reconsidered taking into account that, even if the process of designing should heavily on users' inputs, they

do not necessarily have the competencies required to know what they want and need [84].

Before any of extra features would be incorporated, the design should be validated, implemented and tested in a pilot study to ensure BMQ meets its goal: offering health condition enhancement for chronic patients in Azores. Chronic patients should be recruited for a randomised controlled usability study where the clinical outcomes should be monitored during a period of time and compared against a controlled group - without assess to the mobile app.

Finally, despite the fact that 80% of the participants in the survey expressed their interest in having a mHealth app to support their daily challenges, only 42% were keen to contribute in the design and/or development of this solution. Previous studies have focused on increasing the levels of patient engagement to improve quality of care [93], they should be taken into account in future iterations.

CHAPTER 7

Conclusions

The objective of the master's research project was to investigate how a mHealth smartphone app should be designed to enhance the health related quality-of-life of the chronic patients in the Autonomous Region of the Azores.

To begin with, through the use of User Centred Design principles, a survey was disseminated across the chronic patients in the RAA revealing that the majority of the respondents struggle with limited health literacy levels and low prescribed medication adherence which could explain why patients reports to feel unhealthy more than 1 week per month. Yet, the results showed that *80% of the respondents contemplate mHealth smartphone app as a valuable tool to promote their well-being.*

To explore this potential, design workshops were held online with both chronic patients and health care providers to unveil the most promising design features of a mHealth app to support their well-being. Features like: *tracking* and *export* of health related variables as well as health care *advice* followed by *medication and appointment reminders, literacy, forum* were considered as the most relevant.

Lastly, a high-fidelity prototype of a mHealth smartphone app was designed by incorporating patients and health care providers perspectives. The prototype was challenged against the users' requirements. Through the integration of users' perspectives it confirmed that *an user-friendly customizable design* is paramount to guarantee mHealth smartphone apps fulfil their objectives. Each iteration brought the prototype closer to a final solution where usability is prioritized to ensure users engagement and continuity of use. Without these two, the potential of mHealth tools could be undermined.

A strength of this master's thesis research project was the collaboration with regional chronic disease associations that gave access to chronic ill patients to which the app is to be designed to. This facilitated the integration of both patients and practitioners perspectives through the whole design phase and evaluation.

Based on the contributions of this work, it can be concluded that mHealth smartphone apps are esteemed to promote positively the health outcomes of chronic patients in Azores. Both as a tool to be used by patients for improved health self-management but also as a tool to unfold unforeseen disease information relevant for health care professionals to improve the efficacy of therapeutic solutions. Ultimately, based on the contributions of this research, the implementation of mHealth technologies - such as mHealth app for chronic patients - are strongly encouraged to achieve resource optimization of the future regional health system.

APPENDIX A

Study Ethics Approval - University of Azores

PARECER 40/2020

Registo: Distribuição UAC/2020/20660 - Pedido de Parecer sobre Dissertação de Mestrado

Requerente: Carolina Madeira Ramos do Carmo, do Mestrado em Ciências Biomédicas, da Faculdade de Ciências e Tecnologia, da Universidade dos Açores

Título do Projeto: *Development of a mobile health condition enhancer tool for chronic patients in Azores*

Enquadramento

O Código de Ética da Universidade dos Açores, aprovado pelo Despacho nº 9795/2015, publicado no Diário da República, 2ª série - nº 167, de 27 de agosto de 2015, prevê no nº2 do artigo 3º que "[à] Comissão de Ética compete a emissão de pareceres sobre as questões que forem remetidas à sua apreciação pela comunidade académica, a pronúncia sobre os aspetos éticos dos projetos de investigação submetidos pelos núcleos, centros ou investigadores individuais, bem como a produção de recomendações sempre que se considerem necessárias."

Parecer

A análise da documentação remetida à Comissão permitiu verificar que os procedimentos a adotar salvaguardam os aspetos éticos da investigação.

A Comissão deliberou **aprovar** o projeto "*Development of a mobile health condition enhancer tool for chronic patients in Azores*".

Ponta Delgada, 18 de dezembro de 2020

Os Membros da Comissão de Ética que deliberaram,

APPENDIX B

Direção Regional de Saúde (DRS) support - Email dissemination

Pedido de colaboração na divulgação de inquérito online a doentes com doença crónica - recolha de dados para tese de mestrado (Universidade dos Açores).

Direção Regional da Saúde <SRES-DRS@azores.gov.pt>

Tue 1/19/2021 3:57 PM

To: Centro de Oncologia dos Açores <sres-coa@azores.gov.pt>; João LR. Morais <Joao.LR.Morais@azores.gov.pt>; SRES HSEIT Sec Administração <sres.hseit.secadministracao@azores.gov.pt>; Hospital do Divino Espirito Santo <sres-hdes@azores.gov.pt>; 11070000000 - SRTSS - USI Graciosa <sres-usigraciosa@azores.gov.pt>; SRE - USIFlores <sres-usiflores@azores.gov.pt>; Unidade de Saúde de Ilha de S.Jorge <sres-usisj@azores.gov.pt>; Centro de Saúde de Vila do Porto <sres-csvp@azores.gov.pt>; 11070000000 - SRTSS - Unidade de Saúde da Ilha do Corvo <sres-usic@azores.gov.pt>; Unidade de Saúde da Ilha do Faial - USIFAIAL <sres-usifaial@azores.gov.pt>; 11070000000 - SRES - Unidade de Saúde Ilha do Pico <sres-usip@azores.gov.pt>; 11070000000 - SRTSS - Unidade de Saúde da Ilha Terceira <sres-usit@azores.gov.pt>; SRES-USISMiguel <sres-usismiguel@azores.gov.pt>

Cc: Carolina Madeira Ramos do Carmo <2019104544@uac.pt>; Ana Maria Loureiro Seca <ana.ml.seca@uac.pt>

1 attachments (379 KB)

Pedido+de+colaboração+da+DRS_signed.pdf;

Ex.mo/a(s) Senhor/a(s)
Presidente do Conselho de Administração

Por considerarmos um projeto de interesse na área da saúde, solicitamos a vossa colaboração para a disseminação de um inquérito no âmbito de um trabalho de tese de mestrado em ciências biomédicas da Universidade dos Açores que visa desenvolver uma aplicação móvel (App) que permitirá apoiar diariamente os doentes crónicos no respeitante à autogestão do seu bem-estar e adesão à terapêutica.

Quanto à metodologia requerida, pretende-se que o *link* de acesso ao inquérito, através do qual serão recolhidos os dados-base de trabalho, seja facultado pelo médico assistente, em sede de consulta, aos doentes crónicos com idade superior a 18 anos.

Informações mais detalhadas constam do ofício da orientadora da tese, o qual se encontra em anexo, nomeadamente:
a) Objetivo da tese de mestrado;
b) Indicação do parecer positivo da Comissão de Ética da Universidade dos Açores;
c) Link do inquérito.

Cientes da V. recetividade agradecemos, desde já, toda a atenção dispensada.

Anexo: o indicado

Com os melhores cumprimentos,

[redacted]
Direção Regional da Saúde
Divisão de Apoio Jurídico e Recursos Humanos
Tel.: 295 204 200
Fax: 295 204 252
Morada: Solar dos Remédios - 9701 – 855 Angra do Heroísmo
Email: sres-drs@azores.gov.pt

Pedido de colaboração na divulgação de inquérito online a doentes com doença crónica - recolha de dados para tese de mestrado (Universidade dos Açores).

Direção Regional da Saúde <SRES-DRS@azores.gov.pt>

Tue 1/19/2021 3:57 PM

To: Centro de Oncologia dos Açores <sres-coa@azores.gov.pt>; João LR. Morais <Joao.LR.Morais@azores.gov.pt>; SRES HSEIT Sec Administração <sres.hseit.secadministracao@azores.gov.pt>; Hospital do Divino Espirito Santo <sres-hdes@azores.gov.pt>; 11070000000 - SRTSS - USI Graciosa <sres-usigraciosa@azores.gov.pt>; SRE - USIFlores <sres-usiflores@azores.gov.pt>; Unidade de Saúde de Ilha de S.Jorge <sres-usisj@azores.gov.pt>; Centro de Saúde de Vila do Porto <sres-csvp@azores.gov.pt>; 11070000000 - SRTSS - Unidade de Saúde da Ilha do Corvo <sres-usic@azores.gov.pt>; Unidade de Saúde da Ilha do Faial - USIFAIAL <sres-usifaial@azores.gov.pt>; 11070000000 - SRES - Unidade de Saúde Ilha do Pico <sres-usip@azores.gov.pt>; 11070000000 - SRTSS - Unidade de Saúde da Ilha Terceira <sres-usit@azores.gov.pt>; SRES-USISMiguel <sres-usismiguel@azores.gov.pt>

Cc: Carolina Madeira Ramos do Carmo <2019104544@uac.pt>; Ana Maria Loureiro Seca <ana.ml.seca@uac.pt>

1 attachments (379 KB)

Pedido+de+colaboração+da+DRS_signed.pdf;

Ex.mo/a(s) Senhor/a(s)
Presidente do Conselho de Administração

Por considerarmos um projeto de interesse na área da saúde, solicitamos a vossa colaboração para a disseminação de um inquérito no âmbito de um trabalho de tese de mestrado em ciências biomédicas da Universidade dos Açores que visa desenvolver uma aplicação móvel (App) que permitirá apoiar diariamente os doentes crónicos no respeitante à autogestão do seu bem-estar e adesão à terapêutica.

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Informações mais detalhadas constam do ofício da orientadora da tese, o qual se encontra em anexo, nomeadamente:
a) Objetivo da tese de mestrado;
b) Indicação do parecer positivo da Comissão de Ética da Universidade dos Açores;
c) Link do inquérito.

Cientes da V. recetividade agradecemos, desde já, toda a atenção dispensada.

Anexo: o indicado

Com os melhores cumprimentos,

[redacted]
Direção Regional da Saúde
Divisão de Apoio Jurídico e Recursos Humanos
Tel.: 295 204 200
Fax: 295 204 252
Morada: Solar dos Remédios - 9701 – 855 Angra do Heroísmo
Email: sres-drs@azores.gov.pt


Contacte-nos
808 24 60 24
LINHA DE SAÚDE AÇORES

APPENDIX C

Example documentation submitted for approval - USISM

1. IDENTIFICAÇÃO DO PROJECTO

Título do projeto	Development of a mobile health condition enhancer tool for chronic patients in Azores	
Promotor:		
Investigador Principal: (respetiva afiliação)	Prof. Associada Ana M.L. Seca, Universidade Açores e cE3c- Centre for Ecology, Evolution and Environmental Changes/Grupo de Biodiversidade dos Açores	
Investigador Coordenador (identificação e afiliação)	Dr. Darius Rohani, Department of Health Technology, Technical University of Denmark (DTU)	
Colaborador que submete o projeto (identificação de todos os conflitos de interesse de qualquer investigador/colaborador para o estudo)	Carolina Carmo, mestranda do curso de Ciências Biomédicas, Universidade dos Açores	
Outros colaboradores (identificação e afiliação)		
Conflitos de interesse (identificação de todos os conflitos de interesse de qualquer investigador/colaborador para o estudo)	NA	
Tipo estudo/investigação:	Estudo enquadra-se na tese do Mestrado em Ciências Biomédicas, Universidade dos Açores trata-se um inquérito online	
Método:	Recolha de dados	Inquérito online disponível em www.omeubemestar.pt
	Confidencialidade e uso dos registos	O tratamento dos dados obtidos garante o anonimato dos participantes, nunca sendo feito qualquer tipo de uso que possa revelar a identidade dos participantes.
	Respeito pelo Regulamento Geral sobre proteção de dados (EU) 2016/679 de 27 de Abril, assegurado?	Sim, Todos os dados recolhidos serão armazenados de forma a permitir a conformidade com a legislação portuguesa e da União Europeia relativa à proteção de dados e à privacidade.
Existem outros centros, onde seja efetuado?	Sim - ☒ Quais? Todas as US das ilhas dos Açores. Não ☐	
Descreva sucintamente o(s) objetivo(s):	Gerais	O estudo enquadra-se no trabalho de tese do Mestrado em Ciências Biomédicas, Universidade dos Açores, onde se propõe desenvolver uma aplicação móvel(App) que permita apoiar as pessoas com doenças crónicas nos desafios diários devido ao seu estado de saúde.
	Específicos	Para criar uma App eficaz, é necessário conhecer as necessidades, as preferências e os desafios com que se debatem os doentes crónicos na RAA na gestão diária do seu bem-estar. Para tal foi criado um inquérito online, destinado a estes doentes com idade superior a 18 anos, com o objetivo de recolher informação relativa a: (i) dados epidemiológicos; (ii) adesão à medicação e regimes terapêuticos; (iii) nível de literacia em saúde e uso de produtos naturais; (iv) indicadores de estado de saúde mental.

Encargos e situações especiais:

Envolvimento de pessoal administrativo - Indique o tipo, frequência e duração prevista. Especifique se o tempo ocupado com a sua colaboração se destina especialmente para esta investigação ou seria executado no âmbito dos cuidados assistenciais habituais a prestar ao doente.	Pede-se ao pessoal administrativo assim como ao clínico que divulgue o inquérito junto de todas as Unidades de Saúde da Ilha de São Miguel (USISM) enviando um email motivando a participação de doentes crónicos. O inquérito está disponível em www.omeubemestar.pt e tem um tempo estimado de resposta de 5-10min. Serão também enviados panfletos para afixar nas salas de espera assim como pequenos panfletos para serem entregues aos pacientes na receção das USISM.

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Telefone: 296 203 000 . Fax Geral: 296 203 090
Email: Helio.TM.Oliveira@azores.gov.pt

Consultas/entrevistas de seguimento - Especifique se as consultas são feitas especialmente para esta investigação ou seriam executadas no âmbito dos cuidados médicos habituais a prestar ao doente.	Não é necessária uma consulta especifica. Apenas que os médicos motivem os seus pacientes com doenças crónicas a participar no inquérito.
- Especifique se os entrevistadores estão obrigados ao segredo médico ou em alternativa se assinaram um acordo de confidencialidade com a instituição.	NA
Encargos financeiros: - Especifique os custos para a Instituição que não estejam abrangidos na prestação dos cuidados de saúde habituais	NA

2. JUSTIFICAÇÃO CIENTIFICA DA INVESTIGAÇÃO

Descreva sucintamente os fundamentos científicos:

Segundo dados publicados pelo Serviço Nacional de Saúde (SNS), as doenças crónicas representam atualmente 70 a 80% dos orçamentos dos sistemas de saúde na Europa, enquanto o inquérito Regional de Saúde editado pela Direção Regional de Saúde (DRS) em 2014 aponta para que mais de metade (51.5%) da população da RAA sofra de doenças crónicas.

Qual é a lacuna no conhecimento que procura responder?

Para responder à crescente necessidade de recursos do sistema nacional de saúde, é necessário promover o uso de tecnologias de proximidade e rápida evolução (como aplicações de telemóvel específicas), e envolver mais o paciente na gestão do seu bem-estar.

É neste âmbito que, a Lic. Carolina Madeira Ramos do Carmo irá desenvolver sob a minha orientação, o seu trabalho de tese de Mestrado em Ciências Biomédicas da Universidade dos Açores intitulado "Development of a mobile health condition enhancer tool for chronic patients in Azores". Pretende-se desenvolver uma aplicação móvel (App) que permita apoiar as pessoas com doença(s) crónica(s), nos seus desafios diários decorrentes dessa(s) doença(s) (por exemplo, necessidade, ou não, de lembretes de toma de medicação, aumento da literária para a saúde…).

3. SUJEITOS

Número (Previsto incluir)	Critérios de inclusão:	Critérios de Exclusão:	Sim	Não
300	Doentes crónicos entre os 18 e os 70 anos	As mulheres Grávidas	☐	☒
		Menores	☒	☐
		Os doentes com perturbações psíquicas	☐	☒
		Os indivíduos com compreensão comprometida	☐	☒
Seleção voluntária da população?			☒	☐

4. PLANO DE INVESTIGAÇÃO

Descrição resumida (cronograma)	Desenho do questionário> disseminação do questionário> recolha de dados e análise		
Data prevista de inicio	19/ 01/ 2021	Data prevista de fim	15/ 04/ 2021

5. CONSENTIMENTO

Quem presta informação?	Os profissionais de saúde que divulguem aos pacientes com o apoio da investigadora, se necessário.
Inclui consentimento esclarecido escrito?	Sim ☒
	Não ☐ Justifique:
Certificação da compreensão da informação	Ver anexo

No caso de menores e inimputáveis, juntar folha de consentimento para os representantes legais.
Caso o menor disponha de capacidade de entendimento e manifestação de vontade é necessário também o seu consentimento, sendo o mesmo obrigatório a partir dos 14 anos.

6. BENEFICIOS PARA A POPULAÇÃO DE ESTUDO/INSTITUIÇÃO

Que benefícios potenciais resultarão do estudo para a população visada?	A aplicação móvel (App) que permita apoiar as pessoas com doença(s) crónica(s), nos seus desafios diários decorrentes dessa(s) doença(s) (por

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	exemplo, necessidade, ou não, de lembretes de toma de medicação, aumento da literária para a saúde…) melhorando o seu bem-estar geral.
Que benefícios potenciais resultarão do estudo para a instituição?	A instituição e os seus funcionários beneficiarão no melhoria de utilização dos seus recursos uma vez que os seus pacientes crónicos terão mais literacia de saúde e facilidade em seguir os regimes terapêuticos recomendados pelos médicos. Suplementariamente, será possível através da ferramenta - se considerado necessário após este estudo - ter um histórico dos dados essenciais para verificar a eficácia das terapias aconselhadas pelos médicos.

7. POTENCIAIS RISCOS PARA A POPULAÇÃO DE ESTUDO/INSTITUIÇÃO E QUESTÕES ÉTICAS ENVOLVIDAS

A população alvo incorre em algum risco adicional por participar no estudo? Especifique	Não
Questões éticas potencialmente envolvidas?	NA
Os dados pessoais colhidos neste estudo serão disponibilizados para outras investigações?	Sim ☐ Quais? Não ☒

8. DOCUMENTOS ANEXAR

	Sim	Não Aplicável
Resumo Curricular do Investigador Principal (assinalando as competências especificas para a investigação que propõe)	☒	
Termo de Responsabilidade Assinado	☒	
Declaração de conflito de interesse	☒	
Autorização do Diretor do Serviço	☒	
Acordo/Protocolo financeiro	☐	☒
Protocolo do Projeto de Investigação	☒	
Modelo de consentimento informado	☒	☐
Resumo das características do medicamento. (só se este possuir AIM).	☐	☒
Apólice de Seguro.	☐	☒
Declaração de responsabilidade civil do Promotor por danos causados pelo fármaco caso não esteja especificado no seguro	☐	☒
Ofício dirigido ao Presidente do Conselho de Administração do HDES solicitando autorização para a efetivação do estudo	☒	
Ofício dirigido ao Presidente da CES do HDES sobre o assunto.	☒	

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Telefone: 296 203 000 . Fax Geral: 296 203 090
Email: Helio.TM.Oliveira@azores.gov.pt

COMISSÃO DE ÉTICA PARA A SAÚDE

Titulo do Estudo:

Data de atribuição de Relatores: / /

Relator 1:

Relator 2:

Pareceres dos relatores:

Parecer da CES:

Av. D. Manuel I . 9500 - 370 Ponta Delgada . São Miguel . Açores . Portugal
Telefone: 296 203 000 . Fax Geral: 296 203 090
Email: Helio.TM.Oliveira@azores.gov.pt

TERMO DE RESPONSABILIDADE

Eu, Carolina Carmo sob a orientação da Prof. Ana M.L. Seca abaixo assinado, na qualidade de investigador principal, declaro por minha honra que as informações prestadas neste questionário são verdadeiras.

Mais declaro que, durante o estudo, serão respeitadas as recomendações respeitantes à realização de experimentação que envolva seres humanos constantes: da Declaração de Helsínquia (retificada na 64ª Assembleia Geral da Associação Médica Mundial, em Fortaleza Brasil, 2013); das Diretrizes Éticas Internacionais para Pesquisas Relacionadas com a Saúde envolvendo Seres Humanos, preparadas pelo Conselho das Organizações Internacionais de Ciências Médicas (CIOMS) em colaboração com a Organização Mundial da Saúde (OMS), de 2016; da Lei de investigação clínica n.º 21/2014, de 16 de Abril; e do Regulamento (EU) n.º 536/2014 do Parlamento Europeu e do Conselho Europeu, de 16 de Abril de 2014 relativo aos ensaios clínicos de medicamentos para uso humano.

Mais me comprometo a informar a CES do HDES de toda e qualquer alteração ao protocolo do estudo, de todo e qualquer resultado não previsto ou reação adversa não prevista durante o mesmo, bem como a enviar a síntese do estudo à CES após a sua conclusão num prazo máximo de 8 semanas.

Ponta Delgada 16 de março de 2021

_____

Av. D. Manuel I . 9500 - 370 Ponta Delgada . São Miguel . Açores . Portugal
Telefone: 296 203 000 . Fax Geral: 296 203 090
Email: Helio.TM.Oliveira@azores.gov.pt

DECLARAÇÃO DE CONFLITOS DE INTERESSE

Eu, Carolina Carmo sob orientação Prof. Ana M.L. Seca abaixo assinado, na qualidade de investigador principal, declaro que nenhum dos Investigadores/Colaboradores apresenta qualquer conflito de interesse com o estudo Development of a mobile health condition enhancer tool for chronic patients in Azores a realizar.

Ponta Delgada 16 de março de 2021

_____

Av. D. Manuel I . 9500 - 370 Ponta Delgada . São Miguel . Açores . Portugal
Telefone: 296 203 000 . Fax Geral: 296 203 090
Email: Helio.TM.Oliveira@azores.gov.pt

Declaração de Consentimento Informado, Esclarecido e Livre

Participação em Estudos de Investigação

Designação do Estudo:

Desenvolvimento duma ferramenta móvel para promover o bem-estar dos doentes crónicos nos Açores

Identificação dos investigadores e afiliação institucional:

Carolina Carmo sob a orientação da Prof. Ana M.L. Seca, Universidade dos Açores

Objetivos e metodologia:

Pretende-se desenvolver uma aplicação móvel (App) que permita apoiar as pessoas com doença(s) crónica(s), nos seus desafios diários decorrentes dessa(s) doença(s). Para criar uma App eficaz, é necessário conhecer as necessidades, as preferências e os desafios com que se debatem os doentes crónicos na RAA na gestão diária do seu bem-estar. Para tal foi criado um inquérito online, destinado a estes doentes com idade superior a 18 anos, com o objetivo de recolher informação relativa a: (i) dados epidemiológicos; (ii) adesão à medicação e regimes terapêuticos; (iii) nível de literacia em saúde e uso de produtos naturais; (iv) indicadores de estado de saúde mental.

Para garantir a privacidade dos doentes e a proteção dos seus dados, a recolha da informação contida no inquérito deverá ser anónima. Isto implica que a sua disponibilização a cada doente crónico não poderá ser feita diretamente pela investigadora. Nestas circunstâncias, solicitamos a colaboração da USISM na divulgação deste projeto e do link do inquérito associado, junto dos profissionais de saúde que contactam diretamente com os doentes crónicos. Assim, poderá ser colocada à consideração de cada doente crónico a possibilidade de participarem no inquérito, a título particular, disponibilizando-lhes o link **www.omeubemestar.pt.**

É de livre vontade que aceito participar no estudo supramencionado, reconhecendo que:

- Compreendi o âmbito de realização do estudo e os seus objetivos;
- Compreendi toda a informação que me foi transmitida, tendo-me sido dada oportunidade de esclarecer todas as minhas dúvidas;
- Foi-me assegurada a confidencialidade de toda a informação obtida e de que a mesma só será utilizada no âmbito da investigação proposta;
- A minha participação no estudo é voluntária e posso interrompê-la a qualquer momento, sem nenhum tipo de penalização por este facto;
- A informação recolhida pode ser utilizada em apresentações científicas, desde que assegurado o anonimato dos participantes.

Data: ___/ ___ /20___

Assinatura do Participante: ______________________________

Assinatura do Investigador: ______________________________

- -

(Devolver ao participante)

Nome do Investigador: Carolina Carmo sob a orientação da Prof. Ana M.L. Seca, Universidade dos Açores

Contactos:

Email: 2019104544@uac.pt

Telefone: (+351) 916 296 169

TERMO DE CONSENTIMENTO INFORMADO

O tratamento dos dados obtidos garante o anonimato dos participantes, nunca sendo feito qualquer tipo de uso que possa revelar a identidade dos participantes. Nenhum dado será tornado público sem o prévio consentimento dos interessados. A recolha e análise de dados deste estudo serão integradas numa dissertação de mestrado e artigo(s) científico(s). A tese e artigo(s) científico(s) não conterão quaisquer dados pessoais que possam revelar direta ou indiretamente a identidade de uma pessoa singular.

Todos os dados recolhidos serão armazenados de forma a permitir a conformidade com a legislação portuguesa e da União Europeia relativa à proteção de dados e à privacidade.

A seguinte frase é apresentada no cabeçalho do questionário aos participantes:

"O questionário abaixo enquadra-se no trabalho de tese do Mestrado em Ciências Biomédicas, Universidade dos Açores, onde se propõe desenvolver uma aplicação móvel(App) que permita apoiar as pessoas com doenças crónicas nos desafios diários devido ao seu estado de saúde.

Para criar uma App eficaz, a sua contribuição é muito valiosa. Este questionário foi criado com o objetivo de conhecer as suas necessidades e preferências do seu bem-estar no dia-a-dia.

Muito obrigada pela sua contribuição. Graças a ela estaremos um passo mais próximo de oferecer uma App que pretende melhorar a sua qualidade de vida.

Ao preencher este inquérito declara que tomou conhecimento do âmbito e objetivos do projeto a desenvolver e concorda com a utilização dos dados recolhidos para os fins descritos, incluindo a publicação na forma de artigo científico dos principais resultados do estudo. Terá o direito de recusar, a qualquer momento, participar no estudo sem que, por este motivo, seja alvo quer qualquer discriminação."

Ex.mo. Senhor
Presidente do Concelho de
Administração do HDES

Data

16-03-2021

ASSUNTO:

Pedido de autorização para a realização do estudo *"Development of a mobile health condition enhancer tool for chronic patients in Azores"*

Eu, Ana M.L. Seca, venho por este meio solicitar, na condição de investigador principal, a autorização para a efetivação do projeto de investigação *"Development of a mobile health condition enhancer tool for chronic patients in Azores";*

Cumprimentos,

……, Dr.

Ex.mo. Senhor
Presidente da Comissão de Ética do
HDESPD

Data

16-03-2021

ASSUNTO:

Pedido de autorização para a realização do estudo *"Development of a mobile health condition enhancer tool for chronic patients in Azores"*

Eu, Ana M.L. Seca, venho por este meio solicitar, na condição de investigador principal, a autorização para a efetivação do projeto de investigação *"Development of a mobile health condition enhancer tool for chronic patients in Azores";*

Cumprimentos,

……, Dr.

APPENDIX D

Study Ethics Approval - USIs

USIF FAIAL
UNIDADE DE SAÚDE DA ILHA DO FAIAL

Assunto: Parecer relativo ao Pedido de colaboração na divulgação de inquérito online a doentes com doença crónica - recolha de dados para tese de mestrado (Universidade dos Açores).

Foi solicitado o parecer da Comissão de Ética para a Saúde (CES) para a disseminação de um inquérito no âmbito de um trabalho de tese de mestrado em Ciências Biomédicas da Universidade dos Açores que visa desenvolver uma aplicação móvel (App) que permitirá apoiar diariamente os doentes crónicos no respeitante à autogestão do seu bem-estar e adesão à terapêutica, da autoria de **Carolina Madeira Ramos do Carmo,** intitulado **" Development** of a mobile health condicion enhancer tool for chronic patients in Azores".

De referir que o pedido de colaboração foi efetuado à Direção Regional da Saúde que por sua vez solicita cooperação da USIFaial conforme se transcreve "Por considerarmos um projeto de interesse na área da saúde, solicitamos a vossa colaboração para a disseminação de um inquérito no âmbito de um trabalho de tese de mestrado em ciências biomédicas da Universidade dos Açores que visa desenvolver uma aplicação móvel (App) que permitirá apoiar diariamente os doentes crónicos no respeitante à autogestão do seu bem-estar e adesão à terapêutica. Quanto à metodologia requerida, pretende-se que o *link* de acesso ao inquérito, através do qual serão recolhidos os dados-base de trabalho, seja facultado pelo médico assistente, em sede de consulta, aos doentes crónicos com idade superior a 18 anos. Informações mais detalhadas constam do ofício da orientadora da tese".

No ofício anexo, remetido pela professora orientadora da UAç, é afirmado que o projeto da tese e o inquérito têm parecer positivo da Comissão de Ética da Universidade dos Açores, sendo que para garantir a confidencialidade e a proteção de dados dos utentes, a recolha da informação deverá ser anónima, o que a acontecer terá de ser através da divulgação do link aos profissionais de saúde que contatam diariamente com os seus doentes crónicos, colocando à sua consideração a possibilidade de participarem no estudo, a título particular, disponibilizando o link para o efeito: www.omeubemestar.pt, não podendo a sua disponibilização ser efetuada diretamente pela investigadora.

Pode constatar-se igualmente no ofício, tratar-se de um inquérito dirigido a doentes com idade superior a 18 anos e tem como objetivo recolher informação relativa a: "dados epidemiológicos; adesão à medicação e regimes terapêuticos; nível de literacia em saúde e uso de produtos naturais e indicadores de estado de saúde mental".

De acordo com a informação descritiva do ofício remetido e da visualização do conteúdo do questionário disponível no link cedido, é assegurado o consentimento informado e a manutenção do anonimato dos participantes, constando ainda que o projeto da tese e o inquérito têm parecer positivo da Comissão de Ética da Universidade dos Açores, referindo ainda a disponibilidade em ceder os resultados do inquérito após a conclusão da Tese de Mestrado, não tendo no entanto o projeto da investigação sido disponibilizado a esta Comissão de Ética.

Perante o exposto a CES entende formular as seguintes recomendações:

(i) A autora deve apresentar o projeto de investigação;

(ii) Deve, ainda, assumir integralmente a responsabilidade pelas garantias de confidencialidade e anonimato dos dados recolhidos no âmbito da respetiva edição e análise;

(iii) Finalmente, os resultados do projeto de investigação deverão ser divulgados na Unidade de Saúde da Ilha do Faial.

Em conclusão, considerando o elencado anteriormente, a CES da USI Faial emite parecer favorável à realização do projeto de investigação intitulado "Development of a mobile health condicion enhancer tool for chronic patients in Azores", condicionado ao cumprimento e apresentação do solicitado no (i) e das demais recomendações formuladas no presente parecer.

A relatora,
Florinda Isabel Martins Costa
Submetido a aprovação em reunião da CES de 04 de fevereiro de 2021

Os membros da CES presentes:

Fátima Lacerda
Florinda Costa
Rui Gregório
Sílvia Escobar

USISM
Unidade de Saúde
da Ilha de São Miguel

DECLARAÇÃO

O Conselho de Administração da Unidade de Saúde da Ilha de São Miguel, declara que reconhece a pertinência e validade do estudo, para a tese de mestrado de Carolina Madeira Ramos do Carmo, que consiste na aplicação online a doentes com doença crónica, mostrando assim a sua vontade na participação e desenvolvimento do mesmo.

Contudo, para garantir que os princípios éticos são respeitados, solicita-se o parecer da Comissão de Ética do HDES

Ponta Delgada, 24 de agosto de 2020

Sandra Silva

Vogal Executiva do Conselho de Administração

Unidade de Saúde da Ilha de São Miguel

Hospital do Divino Espírito Santo de Ponta Delgada, EPER

Região Autónoma dos Açores

Secretaria Regional da Saúde
Direção Regional da Saúde
Hospital Divino Espírito Santo de Ponta Delgada, EPER

V/Referência

DATA:

Ex.mo(a). Senhor(a)
Dra. Carolina Carmo

N/Referência
S-HDES/2021/708
DATA: 22/09/2021

Assunto: Projeto de investigação "Development of a mobile health condition enhancer tool for ghronic patients in Azores"

Encarrega-me o Conselho de Administração do HDESPD, EPER, de informar a V. Exa. de que foi autorizado na RCA 003 de setembro 2021, realizada em 21-09-2021 a realização do projeto de investigação "Development of a mobile health condition enhancer tool for ghronic patients in Azores no Hospital do Divino Espirito Santo" do qual V. Exa. é investigadora principal, após parecer favorável da Comissão de Ética para a Saúde deste Hospital.

Com os melhores cumprimentos,

Presidente do Conselho de Administração

Dra. Cristina Fraga

Contactos

Endereço
HOSPITAL DIVINO ESPÍRITO SANTO
AVENIDA D. MANUEL I, MATRIZ
9500-370 PONTA DELGADA
SÃO MIGUEL - AÇORES

E-mail
sres-hdes@azores.gov.pt

Telefone/Fax
296 203 000
296 203 050

Website
http://.hdes.pt

[redacted]

De: Direção Regional da Saúde
Enviado: 19 de janeiro de 2021 15:03
Para: 11070000000 - SRTSS - USI Graciosa; SRE - USIFlores; Unidade de Saúde de Ilha de S.Jorge; Centro de Saúde de Vila do Porto; 11070000000 - SRTSS - Unidade de Saúde da Ilha do Corvo; Unidade de Saúde da Ilha do Faial - USIFAIAL; 11070000000 - SRES - Unidade de Saúde Ilha do Pico; 11070000000 - SRTSS - Unidade de Saúde da Ilha Terceira; SRES-USISMiguel
Cc: 2019104544@uac.pt; ana.ml.seca@uac.pt
Assunto: Pedido de colaboração na divulgação de inquérito online a doentes com doença crónica - recolha de dados para tese de mestrado (Universidade dos Açores).
Anexos: Pedido+de+colaboração+da+DRS_signed.pdf

Ex.mo/a(s) Senhor/a(s)
Presidente do Conselho de Administração

Por considerarmos um projeto de interesse na área da saúde, solicitamos a vossa colaboração para a disseminação de um inquérito no âmbito de um trabalho de tese de mestrado em ciências biomédicas da Universidade dos Açores que visa desenvolver uma aplicação móvel (App) que permitirá apoiar diariamente os doentes crónicos no respeitante à autogestão do seu bem-estar e adesão à terapêutica.

Quanto à metodologia requerida, pretende-se que o *link* de acesso ao inquérito, através do qual serão recolhidos os dados-base de trabalho, seja facultado pelo médico assistente, em sede de consulta, aos doentes crónicos com idade superior a 18 anos.

Informações mais detalhadas constam do ofício da orientadora da tese, o qual se encontra em anexo, nomeadamente:
a) Objetivo da tese de mestrado;
b) Indicação do parecer positivo da Comissão de Ética da Universidade dos Açores;
c) Link do inquérito.

Cientes da V. recetividade agradecemos, desde já, toda a atenção dispensada.

Anexo: o indicado

Com os melhores cumprimentos,

[redacted]
Direção Regional da Saúde
Divisão de Apoio Jurídico e Recursos Humanos
Tel.: 295 204 200
Fax: 295 204 252
Morada: Solar dos Remédios - 9701 – 855 Angra do Heroísmo
Email: sres-drs@azores.gov.pt

Contacte-nos
808 24 60 24
LINHA DE SAÚDE AÇORES

OK. encaminhar. responder com novo parecer favorável.
16/3/2021

Pedido de colaboração na divulgação de inquérito online a doentes com doença crónica - recolha de dados para tese de mestrado (Universidade dos Açores

[redacted]

Thu 4/22/2021 4:45 PM

To: Carolina Madeira Ramos do Carmo <2019104544@uac.pt>

Serve o presente para informar de que, foi deliberado em sessão do Conselho de Administração, de 15 de abril de 2021, aprovar o seu pedido, tendo por base o parecer da comissão de ética e não implicação de custos.

Com os melhores cumprimentos.

[redacted]

O Secretariado do Conselho de Administração da USI Terceira

USITERCEIRA
Unidade de Saúde da Ilha Terceira

Acreditação da Qualidade pelo Ministério da Saúde *(ACSA International)*: NÍVEL BOM

Canada dos Melancólicos, 9701-869 Angra do Heroísmo
Telefone: +351 295 402 900 E-mail: sres-usit@azores.gov.pte Site: https://usiterceira azores.gov.pt/

APPENDIX E

Investigative methods - Survey

App + bem-estar para doentes crónicos

O questionário abaixo enquadra-se no trabalho de tese do Mestrado em Ciências Biomédicas, Universidade dos Açores, onde se propõe desenvolver uma aplicação móvel(App) que permita apoiar as pessoas com doenças crónicas nos desafios diários devido ao seu estado de saúde.

Para criar uma App eficaz, a sua contribuição é muito valiosa. Este questionário foi criado com o objetivo de conhecer os seus desafios e as suas preferências para o seu bem-estar no dia-a-dia.

O tempo estimado de resposta é 5-10 minutos.

Muito obrigada pela sua contribuição. Graças a ela estaremos um passo mais próximo de lhe oferecer uma App que pertende melhorar a sua qualidade de vida.

Ao preencher este inquérito declaro que tomei conhecimento do âmbito e objetivos do projeto a desenvolver e concordo com a utilização dos dados recolhidos para os fins descritos, incluindo a publicação na forma de artigo científico dos principais resultados do estudo. Terá o direito de recusar, a qualquer momento, participar no estudo sem que, por este motivo, seja alvo quer qualquer discriminação.

*Obrigatório

1. Em que ilha vive neste momento? *

Marcar apenas uma oval.

- Corvo
- Faial
- Flores
- Graciosa
- Pico
- Santa Maria
- São Jorge
- São Miguel
- Terceira

2. Idade *

3. Sexo *

Marcar apenas uma oval.

- ◯ Feminino
- ◯ Masculino

4. Qual o seu peso atual (kg)? *

5. Qual a sua altura (m)? *

6. Como considera, em geral o seu estado de saúde? *

Marcar apenas uma oval.

- ◯ Excelente
- ◯ Bom
- ◯ Normal
- ◯ Mau

7. Considerando a sua saúde física, que inclui doença física ou lesões, quantos dias no último mês considerou o seu estado de saúde física "mau"? *

8. Considerando a sua saúde mental, que inclui stress, depressão e problemas emotivos, quantos dias no último mês considerou o seu estado de saúde mental "mau"? *

_____

9. No último mês, quantos dias a sua má saúde fisica ou mental prejudicou as suas atividades diárias? *

_____

10. Tem doença(s) crónica(s)? Entende-se por doença crónica a qualquer doença que afecte a sua saúde física ou mental durante um periodo superior a um ano e não tenha cura. *

Marcar apenas uma oval.

- ◯ Sim *Avançar para a pergunta 11*
- ◯ Não *Avançar para a pergunta 22*

Medicação e autogestão da doença

A "autogestão da doença" é definida como o conjunto de atividades tomadas pelo indivíduo, família ou comunidade para melhorar a saúde, prevenir ou limitar as consequências da doença no dia-a-dia.

11. De que doença(s) crónica(s) sofre? *

Marcar apenas uma oval.

- ◯ Hipertensão
- ◯ Obesidade ou pre-obesidade
- ◯ Dor crónica
- ◯ Doença reumática
- ◯ Doença genética
- ◯ Diabetes
- ◯ Outra: _____

12. Nas últimas duas semanas houve dias em que não tomou a sua medicação? *

Marcar apenas uma oval.

- ◯ Sim
- ◯ Não

13. Alguma vez deixou de tomar a medicação porque se sentia pior quando a tomava? *

Marcar apenas uma oval.

- ◯ Sim
- ◯ Não

14. Quando viaja ou sai de casa alguma vez se esqueceu de levar a sua medicação? *

Marcar apenas uma oval.

- ◯ Sim
- ◯ Não

15. Tomou a sua medicação ontem? *

Marcar apenas uma oval.

- ◯ Sim
- ◯ Não

16. Quando sente que a sua saúde está sob controlo, deixa por vezes de tomar a sua medicação? *

Marcar apenas uma oval.

- ◯ Sim
- ◯ Não

17. Com que frequência se esquece da sua medicação? *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Ás vezes
- ◯ Frequentemente
- ◯ Sempre

18. É difícil seguir o seu plano de medicação? *

Marcar apenas uma oval.

- ◯ Sim
- ◯ Não

19. Quais os fatores que podem dificultar seguir o plano medicação? *

Marcar apenas uma oval.

- ◯ Rotina do dia-a-dia muito variada
- ◯ Toma de vários tipos de medicamentos
- ◯ Constragimento em tomar medicação em frente a terceiros
- ◯ Dificuldades financeiras
- ◯ Outra: _____

20. Consegue sem ajuda de terceiros perceber quando a sua doença crónica entra numa fase de instabilidade/desiquilíbrio? *

Marcar apenas uma oval.

- ◯ Sim
- ◯ Não

21. Quando os sintomas da doença crónica se acentuam a quem recorre para obter ajuda para voltar a estabilizar? *

Marcar tudo o que for aplicável.

- ☐ Médico ou outro profissional de saúde
- ☐ Familiares
- ☐ Conhecidos
- ☐ Ninguém

Outra: ☐ _____

Literacia na saúde

A Organização Mundial da Saúde define literacia na saúde como o conjunto de "competências cognitivas e sociais e também, a capacidade dos indivíduos de entenderem e usarem informação de forma a promover e manter a sua saúde".

22. Sinto-me compreendido e apoiado pelo meu médico. *

Marcar apenas uma oval.

- Nunca
- Às vezes
- Sempre

23. Consigo seguir as indicações do meu médico para a gestão do meu bem-estar. *

Marcar apenas uma oval.

- Nunca
- Às vezes
- Sempre

24. Entendo as indicações do meu médico para a gestão do meu bem-estar. *

Marcar apenas uma oval.

- Nunca
- Às vezes
- Sempre

25. Entendo a informação que acompanha os medicamentos e/ou equipamentos médicos que utilizo. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

26. Considero que tenho informação/conhecimento suficiente para manter o meu bem-estar. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

27. Sou eu que faço a gestão da minha própria saúde. *

Marcar apenas uma oval.

- ◯ Nunca *Avançar para a pergunta 30*
- ◯ Às vezes *Avançar para a pergunta 28*
- ◯ Sempre *Avançar para a pergunta 28*

Avançar para a pergunta 28

28. Faz planos de práticas saudáveis (alimentação, exercício físico, etc.) para garantir que faz o necessário para manter o seu bem-estar? *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

29. Segue esses planos de saúde que faz para si? *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

30. Tenho apoio social (familiares, amigos, conhecidos) para a gestão da minha saúde. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

31. Encontro facilmente informação sobre problemas de saúde. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

32. Sinto-me capaz de compreender a informação de saúde que recebo/encontro. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

33. Quando recebo nova informação de saúde, vou confirmar a sua veracidade. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

34. Comparo informação de saúde de diferentes fontes e decido o que é melhor para mim. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

35. Pergunto ao meu médico sobre a qualidade da informação de saúde que encontro. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

36. Sou capaz de conversar sobre os meus problemas de saúde com o meu médico. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

37. Em caso de necessidade, sei encontrar o profissional de saúde que necessito. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

38. Consigo ter acesso aos cuidados do médico ou outro profissional de saúde que necessito. *

Marcar apenas uma oval.

- ◯ Nunca
- ◯ Às vezes
- ◯ Sempre

39. Conheço os cuidados de saúde aos quais tenho direito. *

Marcar apenas uma oval.

- ◯ Discordo
- ◯ Concordo ligeiramente
- ◯ Concordo completamente

40. Sente que o uso de produtos naturais podem contribuir para o seu bem-estar? *

Marcar apenas uma oval.

- ◯ Sim
- ◯ Não
- ◯ Depende do produto natural

41. Usa produtos naturais para o seu bem-estar? *

Marcar apenas uma oval.

- ◯ Não *Avançar para a pergunta 43*
- ◯ Às vezes *Avançar para a pergunta 42*
- ◯ Frequentemente *Avançar para a pergunta 42*

Exemplos produtos naturais

42. Indique exemplo(s) de produtos naturais que use para beneficiar o seu bem-estar: *

_____

Saúde mental

Nas últimas duas semanas...

43. ...tem conseguido manter-se concentrado/a no que faz? *

Marcar apenas uma oval.

- ◯ Mais do que o habitual
- ◯ Como habitualmente
- ◯ Menos do que o habitual
- ◯ Muito menos do que o habitual

44. ...tem perdido horas de sono por preocupações? *

Marcar apenas uma oval.

- Não
- Como habitualmente
- Mais do que o habitual
- Muito mais do que o habitual

45. ...tem-se sentido útil nos desafios do seu dia-a-dia? *

Marcar apenas uma oval.

- Mais do que o habitual
- Como habitualmente
- Menos do que o habitual
- Muito menos do que habitual

46. ...tem conseguido tomar decisões? *

Marcar apenas uma oval.

- Melhor do que habitual
- Como habitualmente
- Pior do que o habitual
- Muito pior do que o habitual

47. ...tem se sentido sob pressão? *

Marcar apenas uma oval.

- Não
- Como habitualmente
- Mais do que o habitual
- Muito mais do que o habitual

48. ...tem conseguido ultrapassar as suas dificuldades? *

Marcar apenas uma oval.

- Não
- Como habitualmente
- Mais do que o habitual
- Muito mais do que o habitual

49. ...tem disfrutado das suas actividades do dia-a-dia? *

Marcar apenas uma oval.

- Mais do que o habitual
- Como habitualmente
- Menos do que o habitual
- Muito menos do que o habitual

50. ...tem conseguido enfrentar os seus problemas? *

Marcar apenas uma oval.

- ◯ Mais do que o habitual
- ◯ Como habitualmente
- ◯ Menos do que o habitual
- ◯ Muito menos do que o habitual

51. ...tem-se sentido infeliz ou deprimido/a? *

Marcar apenas uma oval.

- ◯ Nada
- ◯ Como habitualmente
- ◯ Mais do que o habitual
- ◯ Muito mais do que habitual

52. ...tem perdido confiança em si? *

Marcar apenas uma oval.

- ◯ Nada
- ◯ Como habitualmente
- ◯ Mais do que o habitual
- ◯ Muito mais do que o habitual

53. ...tem-se sentido uma pessoa inútil? *

Marcar apenas uma oval.

- ◯ Nada
- ◯ Como habitualmente
- ◯ Mais do que o habitual
- ◯ Muito mais do que o habitual

54. ...tem-se sentido razoavelmente feliz, considerando tudo na sua vida. *

Marcar apenas uma oval.

- ◯ Mais do que o habitual
- ◯ Como habitualmente
- ◯ Menos do que o habitual
- ◯ Muito menos do que o habitual

Interesse na App

55. Consideraria útil ter acesso a uma aplicação móvel (App) que lhe permita minimizar os desafios do dia-a-dia ligados à sua doença crónica? *

Marcar apenas uma oval.

- ◯ Sim
- ◯ Não

56. Interessar-lhe-ia participar e contribuir para o aperfeiçoamento desta aplicação numa sessão de teste? *

Marcar apenas uma oval.

- ◯ Sim
- ◯ Não
- ◯ Talvez

APPENDIX F

Workshop Invitation - Emails

Convite Seminário "Bem Me Quero - Açores"

Carolina Madeira Ramos do Carmo <2019104544@uac.pt>

Fri 6/18/2021 8:00 AM

To: [redacted]

Bom dia,

Convidamo-vos a participar no Seminário "Bem Me Quero - Açores"

Aprenda mais sobre como este projeto pretende promover o bem-estar no dia-a-dia dos doentes crónicos nos Açores.
Será também uma oportunidade de dar a sua opinião e sugestões.
Juntos conseguimos mais e melhor.

Utilizando o link abaixo, poderá partilhar connosco qual a data que mais lhe convem.
Após encontrarmos a data mais conveniente, enviaremos o link para o seminário.

Doodle

Doodle: Bem Me Quero - Açores seminário

Partilhe o seu email ou nr. telefone, para que possamos ajuda-lo caso haja problemas técnicos durante a sessão. Obrigada

link.e.doodle.com

Convite seminário "Bem Me Quero - Açores"

Carolina Madeira Ramos do Carmo <2019104544@uac.pt>
Tue 6/22/2021 7:07 PM
To: [redacted]
Exmo. [redacted],

Muito obrigada pelo seu interesse e disponibilidade.

Como combinado, envio-lhe a informação necessária para participar no Seminário online do projeto "Bem Me Quero - Açores". Peço que confirme que recebeu este convite e que verifique que o link abaixo funciona assim que possível.

Contamos consigo na sexta-feira, dia **2 de julho de 2021 pelas 18h30** via Zoom.

Junte-se a nós usando o seu PC, Mac, Linux, iOS ou Android em:
https://videoconf-colibri.zoom.us/j/83049339634?pwd=cWFtdS95YkMrOWN2OXMyKzZ6a28zUT09

Password: 710479
Meeting ID: 830 4933 9634

Convite "Bem Me Quero - Açores"

Carolina Madeira Ramos do Carmo <2019104544@uac.pt>
Wed 6/30/2021 9:42 AM
To: [redacted]
Bom dia Exmo. [redacted],

Escrevo-lhe este email para confirmar a sua disponibilidade para participar no nosso seminário via Zoom esta **sexta-feira às 18h30** (Açores).
Estamos convencidos que incluir a sua opinião seria uma grande mais-valia para o sucesso deste projeto.

Caso tenha alguma dúvida que gostasse de esclarecer não hesite em contactar-me via email ou +351 916 296 169

Fico a aguardar a sua confirmação com entusiasmo. Obrigada.
Carolina Carmo

Bem Me Quero - Sumário e o que se segue

Carolina Madeira Ramos do Carmo <2019104544@uac.pt>

Mon 7/12/2021 2:53 PM

To: [redacted]

Boa tarde a todos,

Gostaria de agradecer uma vez mais a vossa participação no seminário. Como combinado, abaixo o sumário do que foi discutido e sugerido por vós durante as 2h de "bate-papo" do dia 2 de Julho.

Do meu lado seguem-se agora 2 meses de preparação para o próximo seminário. No 2o seminário espero com enorme entusiasmo celebrar o aniversário da associação ADDCA assim como ter a ocasião de vos apresentar o resultado desenvolvimento da App conforme as vossas sugestões. Será a ocasião de poderem ver em primeira mão a ferramenta que esperamos que vá facilitar o dia-a-dia dos doentes crónicos nos Açores e melhorar o seu bem-estar.

Aproveito a ocasião deste email para pedir aos membros da ADDCA a confirmação da data das celebrações.

Desejo-vos uma excelente semana.
Carolina Carmo

APPENDIX G

Producing Design solutions - Workshop 2.July 2021

Seminário
Aplicação móvel

1

Recomendações

Cameras ligadas

Telefones em silêncio

Alguma coisa para beber e petiscar

Partilhar ideias, não julgar

2

Se eu fosse um animal seria... Porque...

Gato

Cão

Golfinho

Elefante

Milhafre

Macaco

Preguiça

Cavalo

3

Doenças crónicas

Inquérito Regional de Saúde dos Açores, DRS, 2014

Contexto

52%

Consideram o seu estado de saúde razoável, mau ou muito mau.

65%

32%

28%

4

Doenças crónicas prevalentes na população RAA

Inquérito Regional de Saúde dos Açores, DRS, 2014

??%

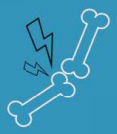
Alergias

26%

Dor crónica

24%

Reúmaticas



23%

5

Objectivo

Como quer o doente crónico nos Açores sentir-se amanhã?

6

Programa

01 Introdução. Bem Me Quero - Açores

02 Resultados inquérito

03 Vamos lá conversar

04 Fim do seminário – sumário e o que se segue

7

01 Introdução

8

01 Introdução
Bem Me Quero Açores

Este projecto está a ser desenvolvido na Universidade dos Açores com o apoio da Direção Regional de Saúde e tem por objetivo desenvolver uma aplicação móvel (App) que permita promover o bem-estar no dia-a-dia dos doentes crónicos nos Açores.

Bem Me Quero AÇORES

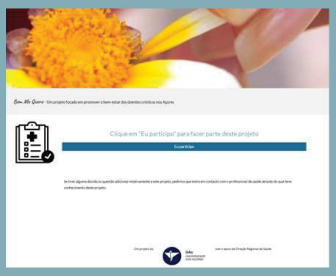
FCT FACULDADE DE CIÊNCIAS E TECNOLOGIA UNIVERSIDADE DOS AÇORES

Direção Regional da Saúde

9

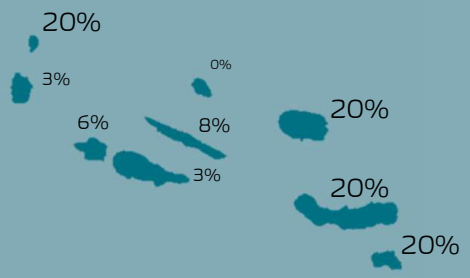
02 Resultados inquérito

Disponível em www.omeubemestar.pt

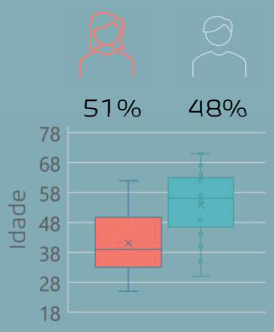


10

Resultados inquérito
Dados epidemiológicos

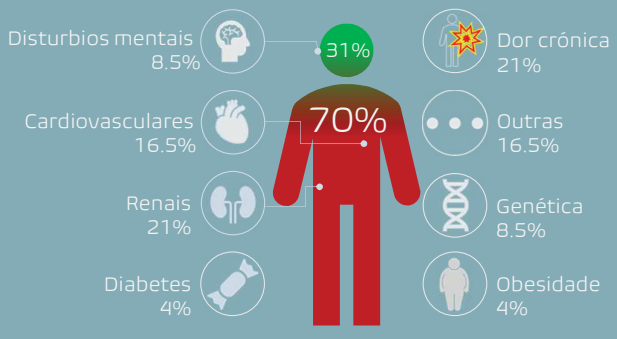


N=36



11

Resultados inquérito
Doentes e doenças crónicas

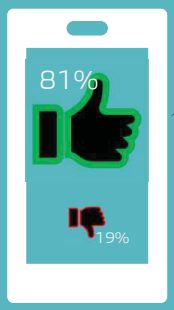


Autodeclarado
N=24

12

Resultados inquérito
Interesse na App

Consideraria útil ter acesso a uma aplicação móvel (App) que lhe permita minimizar os desafios do dia-a-dia ligados à sua doença crónica?



13

03 Vamos lá conversar

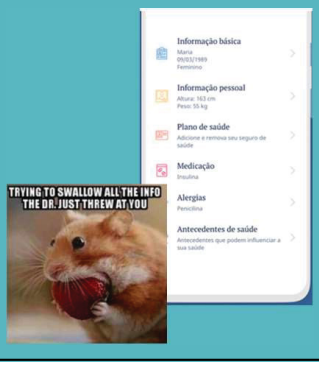
14

03 Vamos lá conversar

Conselhos

Forum

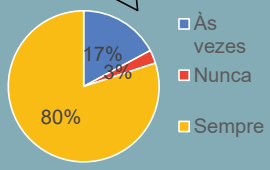
Lembrete



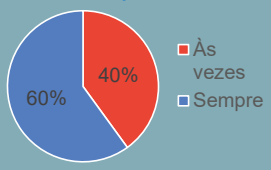
15

Resultados inquérito

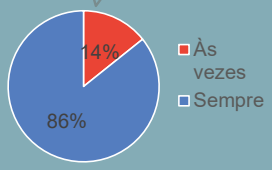
Sinto-me compreendido e apoiado pelo meu médico.



Consigo seguir as indicações do meu médico para a gestão do meu bem-estar.



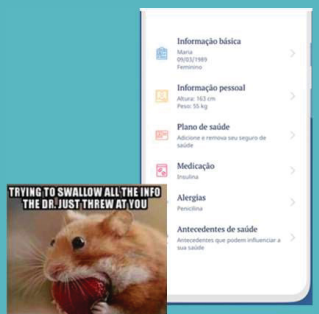
Entendo as indicações do meu médico para a gestão do meu bem-estar.

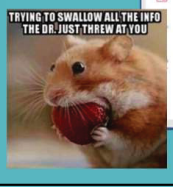


16

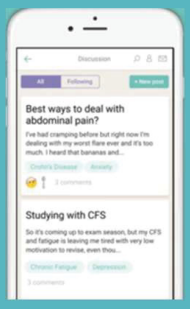
03 Vamos lá conversar

Conselhos





Forum

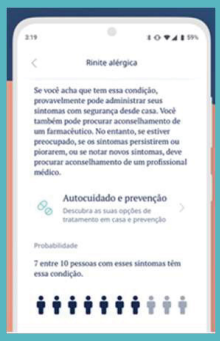


Lembrete

17

03 Vamos lá conversar

Literacia



Agregando dados

18

Resultados inquérito
Uso de productos naturais

Chás, tisanas
43%

Plantas medicinais
20%

Alimentos funcionais
24%

Nutracêuticos
24%

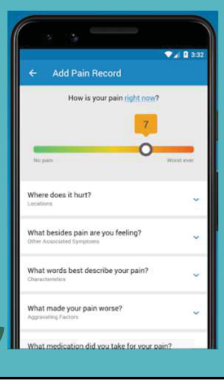
60%

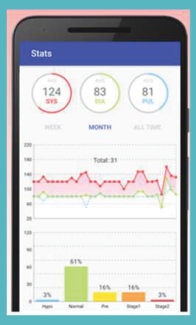
19

03 Vamos lá conversar

Literacia

Agregando dados





20

04 Sumário e o que se segue

21

HOJE

Incompreensão

Medicação a horas

Alimentação. Hidratação.

Tensão arterial

O que interessa é as pessoas se juntem discutam ideias para serem ouvidas.

Uma grande parte da cura parte dos doentes.

Absentismo. Apoio na reintegração

Proposta de decreto-lei para retirar isenções fiscais aos doentes crónicos

Auto-gestão da saúde aplicada a cada patologia. O facto de conhecer a doença ajuda a controla-la.

Politica a nivel nacional deixa muito a desejar. RAA apanha por tabela com muitas legislações.

Os nossos governantes não conhecem muito a realidade

22

Running order

Time	Activity	Output	Who
18:30 -18:35	Mute everyone – Inform participants. Musica	Gather all participants	Carolina
18:35 – 18:37	Round-table Welcome and agenda Recommendations	Clarify expectations	Carolina
18:37 – 18:47	Icebreaker. Sound check one by one. Use tool - sample	Relax participation Test working tools	All
18:47 – 19:15	Que tipos de preocupações tem no dia-a-dia relacionadas com a sua doença?	A user NEEDS xxx because xxx otherwise xxx SAYS-THINKS-DOES-FEELS Find pains	All
After 45	BREAK Turn of mic and camera	Music	Carolina
19:30 – 19:40	Quais são as funcionalidades que mais podem ajudar no dia-a-dia?	SAYS-THINKS-DOES-FEELS Voting	All
19:40– 19:50	Summary		Carolina
Post workshop	Feedback email		

23

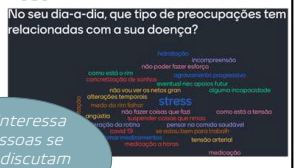
Resumo seminário 2.Jul.2021

Participantes
4 doentes crónicos entre eles, 1 médica

Desafios citados
- Terapêuticos
- Tarefas laborais
- Sociais – familia
- Literacia
- Contexto legal

Soluções recomendadas
- Lembretes
- Diário de dados de saúde
- Conselhos
- Fórum
- Literacia

Pontos chave
- Desafios comuns entre doenças crónicas
- Necessidade de uma voz comum



Testemunhos
"Uma grande parte da cura parte dos doentes"
"Incompreensão"
"O que interessa é as pessoas se juntem, discutam ideias para serem ouvidas"

2021 – O que se segue?

24

O que se segue

2021 — Jul · Ago · Set · Oct · Nov · Dez — 2021 — Jan · Fev · Mar

Fim do desenvolvimento da App

Tese de Mestrado
Escrever
Defender

Rever potencial
Lançar ao público geral.

25

Bem Me Quero AÇORES

Obrigada

FCT FACULDADE DE CIÊNCIAS E TECNOLOGIA UNIVERSIDADE DOS AÇORES

26

When you're chronically ill and you're trying to act normal..

27

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UNIVERSIDADE DOS AÇORES
Faculdade de Ciências e Tecnologia

Rua da Mãe de Deus
9500-321 Ponta Delgada
Açores, Portugal