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DE ARTES E DESIGN

Bridging design and health:

Communication and capacitation processes in a cohort study

Constança Inês Fernandes Paulitos Netto Rocha

Dissertation under the supervision of Professor Elga Patrícia Maximiano Ferreira
and co-supervision of Professor Estêvão Soares dos Santos.

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Dedication

To those who have always had my back and have always believed in me.

Acknowledgements

I dedicate this work to those who have supported me throughout my life.

To my mother for the strength, perseverance, and dedication she taught me to have in everything I do. For her support in the most difficult moments of my life, and for the laughs we share.

To my father whose memory I hold dear.

To my family.

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A final thanks to the institutions that made this possible.

Disclaimer

The author would like to declare that this master's dissertation constitutes an integral part of a Cohort Study taking place in the county of Leiria that involves CML, ciTechCare, ACES Pinhal Litoral, and LIDA.

The author informs that there are multiple papers published and presented in conferences regarding the work accomplished on this project.

- **Poster published in RUN-EU General Assembly** (conference 3rd and 4th Nov 2021 - General Assembly, TUS, Ireland) - "Service Design for stakeholder capacitation in health literacy, in the county of Leiria"

Authors: Netto-Rocha, C., Marques, D.

- **Paper (in press) and presentation in EhSemi 2022** and students' seminar on ehealth and Wellbeing (conference 3rd Feb 2022 - University of Aveiro) - "Design Approaches: Health Literacy capacitation in the County of Leiria"

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Authors: Dias, S., Santos, E., Alves, B., Gabriel, T., Netto-Rocha, C.,
Marques, D., Passadouro, R.

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Designing Cohort Study Guidelines"

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Authors: Netto-Rocha, Constança., Maximiano Ferreira, Elga., Soares
dos Santos, Estêvão.

The author notes that due to protection of data and personal information of the interviewees, the performed interviews will not be attached to this document.

Abstract

The project began on the basis of the *Strategic Health Plan* for the municipality of Leiria developed by Leiria City Council and ACES Pinhal Litoral (ACES Pinhal Litoral, 2019), which showed the high number of people going to the Emergency Room (ER) with minor problems, leading to a flooding of the emergency systems and a high rate of metabolic diseases and comorbidities in the municipality of Leiria. It is hypothesised that this data is being caused by the population's low levels of health literacy. Health literacy is the ability of a person to obtain, read, understand and use health care information to make appropriate health decisions, to use healthcare services and understand treatment instructions given by health professionals (Pedro et al, 2016). Thus, low levels of health literacy in the population can have a negative impact on the quality of health, the way people use and interact with healthcare and, consequently, contribute to high costs for healthcare systems.

Thus, based on the assumption that there are low levels of health literacy among the population of the municipality of Leiria, it was decided to create a cohort study aimed at validating or refuting this assumption. A cohort study is a type of study that follows, monitors and analyses a subject over time ((Hammoudeh et al., 2016; Hulley et al., 2007). This study would follow the population over time to assess whether the actions taken (e.g. information campaigns on healthy behaviours and metabolic diseases) have an impact on the overall health of the population. The first phase of the cohort study includes the presentation and publicising of the study itself to the population,

followed by a door-to-door survey carried out by interviewers. This is the phase to which this project will contribute.

This project is based on applying design methodologies and tools to develop and implement the study. Informal interviews (Kumar, 2013; Martin & Hanington, 2012) will be conducted with the cohort study team, a group of cohort study experts and a sample of the population. The aim of these interviews is to understand the challenges of the study, strategies for resolving them and to understand the factors that contribute to participation in the study. The methodology of defining the user group (Kumar, 2013; Martin & Hanington, 2012; Petermans & Cain, n.d.) will also be applied, conducted to understand the different points of view of the participants, then allowing the creation of personas (B. Ferreira, Conte, et al., 2015; B. M. Ferreira et al., 2016; Ku & Lupton, 2020; Miaskiewicz & Kozar, 2011) consisting of archetypes of the door-to-door survey interviewers, providing a more accurate selection process. Workshops (IDEO, 2015) will also be held, which will serve as a testing ground for the previously developed processes.

Given that this is an ongoing study, the project's own development will define its needs. Due to the high drop-out rates in similar studies, it is hoped that the design intervention in this study can reverse this trend, bridging the gap between what is expected by researchers and the perception of the study population. The ultimate goal is to create a process that can be replicated in other similar studies.

Keywords: Cohort study, Multidisciplinary Team, Service Design, Participative Design, Web Design, Interviews, User Group Definition, Personas

Resumo

O projeto teve início com base no *Plano Estratégico de Saúde* para o concelho de Leiria desenvolvido pela Câmara Municipal de Leiria e pelo ACES Pinhal Litoral (ACES Pinhal Litoral, 2019), que evidenciou o elevado número de pessoas que recorrem ao Serviço de Urgências com problemas menores, levando a uma inundação dos serviços de urgência e uma elevada taxa de doenças metabólicas e comorbilidades no concelho de Leiria. A hipótese é que estes dados estejam a ser causados pelos baixos níveis de literacia em saúde da população. A literacia em saúde é a capacidade de uma pessoa obter, ler, compreender e utilizar a informação sobre cuidados de saúde para tomar decisões de saúde adequadas, utilizar os serviços de saúde e compreender as instruções de tratamento dadas pelos profissionais de saúde (Pedro et al, 2016). Assim, baixos níveis de literacia em saúde na população podem ter um impacto negativo na qualidade da saúde, na forma como as pessoas utilizam e interagem com os cuidados de saúde e, conseqüentemente, contribuir para custos elevados para os sistemas de saúde.

Assim, partindo do pressuposto que existem baixos níveis de literacia em saúde na população do concelho de Leiria, decidiu-se criar um estudo de coorte com o objetivo de validar ou refutar este pressuposto. Um estudo de coorte é um tipo de estudo que segue, monitoriza e analisa um sujeito ao longo do tempo (Hammoudeh et al., 2016; Hulley et al., 2007). Este estudo seguiria a população ao longo do tempo para avaliar se as acções desenvolvidas (por exemplo, campanhas de informação sobre comportamentos saudáveis e doenças metabólicas) têm um impacto na saúde geral da população.

A primeira fase do estudo de coorte inclui a apresentação e a divulgação do próprio estudo à população, seguida de um inquérito porta-a-porta efectuado por entrevistadores. É para esta fase que o presente projeto irá contribuir.

Este projeto baseia-se na aplicação de metodologias e ferramentas de design para desenvolver e implementar o estudo. Serão realizadas entrevistas informais (Kumar, 2013; Martin & Hanington, 2012) à equipa do estudo de coorte, a um grupo de peritos em estudos de coorte e a uma amostra da população. O objetivo destas entrevistas é compreender os desafios do estudo, as estratégias para os resolver e perceber os factores que contribuem para a participação no estudo. Será também aplicada a metodologia de definição do grupo de utilizadores (Kumar, 2013; Martin & Hanington, 2012; Petermans & Cain, n.d.), conduzida para compreender os diferentes pontos de vista dos participantes, permitindo depois a criação de personas (B. Ferreira, Conte, et al., 2015; B. M. Ferreira et al., 2016; Ku & Lupton, 2020; Miaskiewicz & Kozar, 2011) constituídas por arquétipos dos entrevistadores do inquérito porta-a-porta, proporcionando um processo de seleção mais preciso. Também serão realizados workshops (IDEO, 2015), que servirão como campo de testes para os processos desenvolvidos anteriormente.

Dado que este é um estudo em curso, o próprio desenvolvimento do projeto definirá as suas necessidades. Devido às elevadas taxas de desistência em estudos semelhantes, espera-se que a intervenção de conceção deste estudo possa inverter esta tendência, fazendo a ponte entre o que é esperado pelos investigadores e a perceção da população estudada. O objetivo final é criar um processo que possa ser replicado noutros estudos semelhantes.

Palavras-Chave: Estudo de coorte, Equipa Multidisciplinar, Design de Serviços, Design Participativo, Web Design, Entrevistas, Definição de Grupos de Utilizadores, Personas

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Abbreviations and Acronyms

ACES Pinhal Litoral	Healthcare Facilities' Headquarters in the region of Leiria
AUDIT	Alcohol Use Habits Rating Scale
CHL	Leiria Hospital Centre
CiTechcare	Centre for Innovative Care and Health Technology
CML	City Hall of Leiria
ESAD.CR	School of Arts and Design - Caldas da Rainha
FINDRISC	Metabolic Disease Risk Scale
FTND	Fagerstrom Test for Nicotine Dependence
HADS	Anxiety and Depression Questionnaire
HLS-EU-PT	Health Literacy Rating Scale
LIDA	Research Laboratory in Design and Art
LISA	Longitudinal Study of Health Literacy in the county of Leiria
WHO	World Health Organization

Chapter 1. Introduction

The present document describes the project developed for a cohort study taking place in the County of Leiria, which aims to measure the health literacy level of the adult population residing in the area. The project came about due to the necessity to develop an effective communication strategy of the study to the population of Leiria. For this, two students of the master's in design for Health and Well-Being were chosen to take part in the design team responsible for developing and implementing the study. To distinguish between the work developed by each student certain elements of the project were designed individually.

In this work, the importance of integrating designers into the study's multidisciplinary team will be conveyed by describing the process of this integration and their interaction with the stakeholders. Design for Health and Well-Being is a new field of research and practice. For this reason, there is a lack of knowledge in society, in academia and research and even in the design community about its intervention, contents, methodologies, specificities and even its own value. At the beginning of the collaboration, the designers had to go through a period of adaptation and clear some misconceptions about design and what can be achieved through the employment of design research tools and methodologies.

The designers' intervention in the development of the study went far beyond communicating the study as originally intended. This extended to the design of the service, meaning how the study would be operationalised, defining the profile of the team members who will

be in the field, researching, analysing and defining the measures that contribute to participant adherence, assessing how the study questionnaire would be perceived up by participants with different levels of literacy, age, socio-economic class, among others, creating good practice guidelines for each of the implementation phases and creating the Interviewer's Handbook with a compilation of scripts, guidelines and protocols for interviewers to present the study to the population.

This document is divided into two main parts. The first part presents the theoretical background relating to the description of cohort studies, health literacy and the design domain and the methodologies used in the practical dimension. The second part, describes the LISA cohort study and the work carried out by the designers in developing this study. The design methodologies used are described in the order in which they were applied in the project. The process of developing the project's outcomes is then described. And finally, in the last chapter, the final considerations of the collaboration in the LISA cohort study are made.

1.1. Research questions

As explained above, the main challenges were to understand how a designer could be part of a team developing a cohort study, how the domain of design in its processes and methodologies could contribute to the development and implementation of a study of this nature and how to effectively communicate it to the population so that they would participate.

The research questions are:

- How can a designer specialising in the health area become an integral part of a multidisciplinary team? And how can we communicate what Health Design is to the stakeholders?
- How can design processes optimise the development, implementation and progress of this cohort study? How and how important is it for the design field to intervene in the early stages of a cohort study and not just be responsible for developing the study's communication to the population?
- What design methodologies and materials could be used to select and train the interviewers who would interview the population?

| Theoretical Background |

Chapter 2. Cohort studies

2.1. Description

A cohort study is a type of Analytic Observational study where a select group of people are observed through time (Hulley et al., 2007). Analytic studies can be divided into case-control studies, cross-sectional studies and cohort studies (Hammoudeh et al., 2016; Hulley et al., 2007; Setia, 2016; Song & Chung, 2010). Case-control studies, cross-sectional studies, are outside the scope of this research and for this reason will not be explained. In observational studies, the researcher observes and keeps track of a relevant link between an exposure and an outcome, without intervening directly in the study (Song & Chung, 2010). Since cohort studies are usually envisioned and projected to take several years from the first contact until the end outcomes, they can be classified as longitudinal observation studies (Hammoudeh et al., 2016). Through the duration of these studies there are usually “check ins” and “follow ups”.

Cohort studies can also be classified as open or closed, prospective or retrospective. An open cohort study is defined by having a dynamic population sample that can change by losing or adding people over the course of the study’s duration (Vandenbroucke et al., 2007, p. 1631) while a closed cohort study is defined by its original population sample that - apart from participants lost - will never change, not

allowing for any addition of new participants. (Vandenbroucke et al., 2007, p. 1631). A retrospective cohort study is a study where researchers will focus their research on past information and events, conversely, a prospective cohort study will follow their research subjects in time (Song & Chung, 2010).

2.2. Prospective cohort studies

In a prospective cohort study, the researcher determines the sample to be followed over the duration of the study and defines the variables that will be measured (Hulley et al., 2007, p95, p99; Song & Chung, 2010, p2). Depending on the variables being measured there may be several follow up contacts with the sample (Setia, 2016, p23), for example, if the researcher wants to know if by creating health literacy classes the health literacy levels of the studied sample will increase, he might contact them after these classes to collect the required data. However, due to their prospective nature this type of cohort study is faced with some hurdles to cross, due to its long duration, there is an increase in cost and difficulty in gathering and holding participants (especially if it is a closed cohort). All these barriers need to be considered if the research team expects a successful and meaningful study (Hammoudeh et al., 2016, p21)

As previously mentioned, one of the biggest challenges a cohort faces is related to the participants, their gathering and holding, according to (Hammoudeh et al., 2016) “The maximum acceptable limit for loss to follow up is 20%” (p. 17). Also, during the preparatory stages of the study (Hammoudeh et al., 2016, p759; Kristman et al., 2004) the

researchers should take into account the loss to follow-up so that the validity of the study is not compromised. There are however some steps identified by (Hulley et al., 2007) that can help in preventing loss to follow-up they are as follows:

Exclude those likely to be lost:

- Those planning to move;
- People not willing to commit to the study;
- If there is the presence of illnesses;
- Morbidities unrelated to the research.

Gather contact information to allow future contact: *

- Phone, email, address; *
- Social Security number or Healthcare number; *
- Contacts of one or two close people; *
- Doctor's contact. *

Maintain contact:

- By phone: may require calls during weekends and evenings;
- By e-mail, mail with stamps, self-addressed return cards;
- Other: newsletters, token gifts with the study's branding.

For those who are not reached by phone or mail:

- Contact family, friends, or doctors;
- Look for new address through public sources;
- Search for information in hospitals;
- Determine vital status from the National Death Registry.

Always:

- Treat study participants with appreciation, kindness, and respect.

*Assuming the study's participants have given informed consent to the collection of sensitive contact and tracking data for follow-up contact. This informed consent must be validated by an ethics committee to ensure its legality.

List adapted from "Strategies for Minimizing Losses during Follow-up" adapted from Hulley (2007, p. 105)

2.3. Validity

In a study of this nature, according to (Hammoudeh et al., 2018; Jacob & Furgerson, 2012; Marczyk et al., 2005) there are two types of validity: Internal and external. Internal validity refers to the conclusions drawn from the research and how it was conducted, considering the methodologies used, the research initially proposed, if the study fulfilled what it had set out to in the beginning and if there were no deviations due to other variables. If all these requirements are met, then the study's findings can be considered true. External validity is related to the generalisation of the study's findings, if they can be applied to other populations, locations, environments and other times. then the study has a high external validity. If this happens, the same author states that the study has high external validity (Hammoudeh et al., 2018).

These two types of validity create a hierarchy between them, since it is vital for a cohort study to have high internal validity to have external validity (Hammoudeh et al., 2018). According to (Fronteira, 2018, p100) the internal validity of a study of this prospective nature has a high correlation with its loss of follow-up. For example, in a study if most of the lost participants are fertile women, this can lead to a loss of internal validity and, consequently, a loss of external validity. In the sense that the sample loses its random character, to the point of causing a bias in the generalisation of the sample (Hammoudeh et al., 2018, p. 15; Vanderbrook p.1636).

Chapter 3. Health Literacy

3.1. What is Health Literacy?

“Health literacy is the ability to obtain, read, understand, and use healthcare information in order to make appropriate health decisions and follow instructions for treatment” (Hewitt, 2012)

According to (Pedro et al., 2016) different studies have shown that a low or improper level of health literacy can negatively impact health quality, how one uses and interacts with healthcare and costs the system a lot of money. In recent decades, the definition of health literacy has become more complex. (Pedro et al. 2016) also states “the concept of health literacy has changed from a purely cognitive definition to a definition that includes the personal and social components of the individual, assuming the ability to make informed decisions in their everyday life”.

We are currently witnessing an exponential increase and ageing of the world's population, also an increase in chronic diseases such as cancer, obesity, and associated comorbidities, among others (ACES Pinhal Litoral, 2019). This scenario emphasises the importance of prevention and detection in the early stages of disease. It is important to provide citizens with greater knowledge about health so that they can make better decisions about their own health and their family members'. Specifically, decisions and actions about lifestyle, screening or treatment options and long-term disease management.

(Pedro et al., 2016) point out that several authors (Baker et al., 1996; Bennet et al., 1998; Davis et al., 1996; Hopper et al., 1998; Kallichman et al., 1999) indicate that individuals with low health literacy are less likely to: “(i) understand written and oral information provided by health professionals; (ii) be able to navigate the health system to obtain the necessary services; (iii) carry out the necessary procedures; and (iv) follow prescribed indications” (p.261).

For all the reasons mentioned, it is important to measure the population's health literacy levels to better adapt the strategies to be applied to promote health literacy.

3.2. European and Portuguese health literacy levels

In a study, (Pedro et al., 2016), published in the “Revista Portuguesa de Saúde Publica” (Portuguese Magazine of Public Health, the European health literacy survey HSL-EU used in eight European countries – Austria, Bulgaria, Germany, Greece, Ireland, Netherlands, Poland, and Spain (Figure 1) – was adapted and used in Portugal. This measuring instrument was developed by (Sørensen et al., 2012) and consists of 47 questions designed to measure the population's literacy levels in the domains of health care (HC), disease prevention (DP) and health promotion (HP). The evaluation scale assigns four levels of health literacy: insufficient, problematic, sufficient and excellent in each domain.

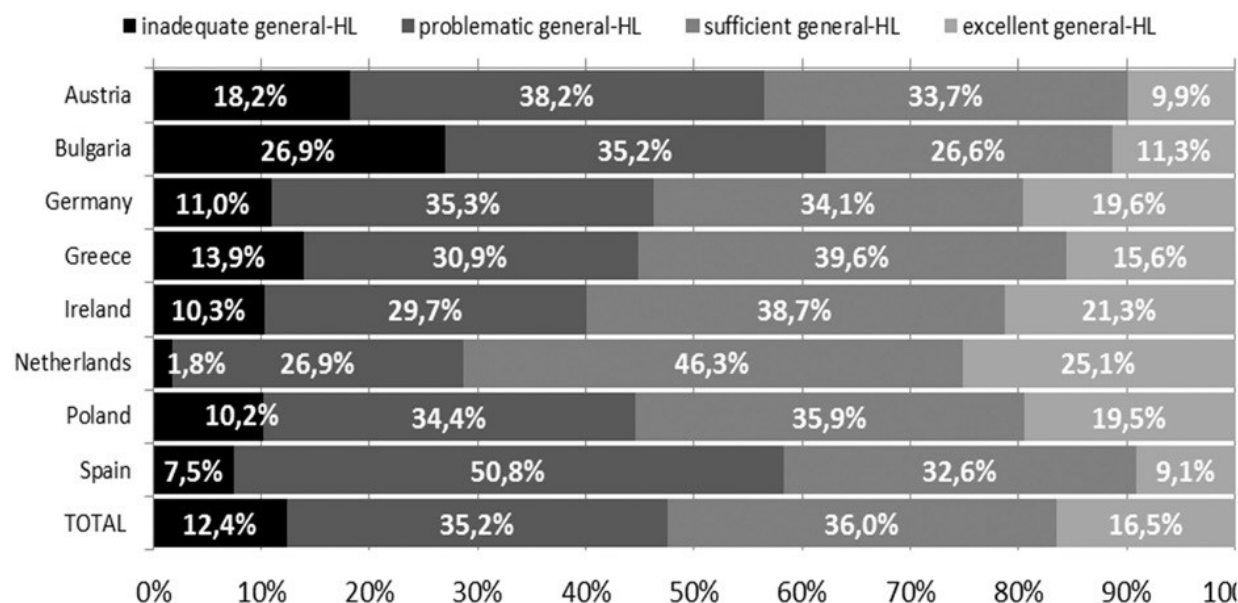


Figure 1. Levels of general health literacy index by country and for the total sample (HL: health literacy) taken from (Sørensen et al., 2012).

The HSL-EU was used and adapted in the HSL-EU-PT to understand the health literacy levels of the Portuguese population and to compare the results with the average of the other European countries tested. It found that the Portuguese population is below average when it comes to health literacy (compared to the other eight tested countries) as can be seen in the figure below (Figure 2).

In Portugal, 61,4% of the population surveyed has a “problematic” or “inadequate level” of general health literacy, while the average for the 8 other countries is 47.6%.

Regarding the health care (HC) dimension, only 44.2% have a sufficient or excellent level of health literacy. As far as disease prevention (DP) is concerned, around 45% of those questioned had a sufficient or excellent level of health literacy- In the health promotion (HP) dimension, 60.2% of the population surveyed had a problematic or inadequate level of health literacy.

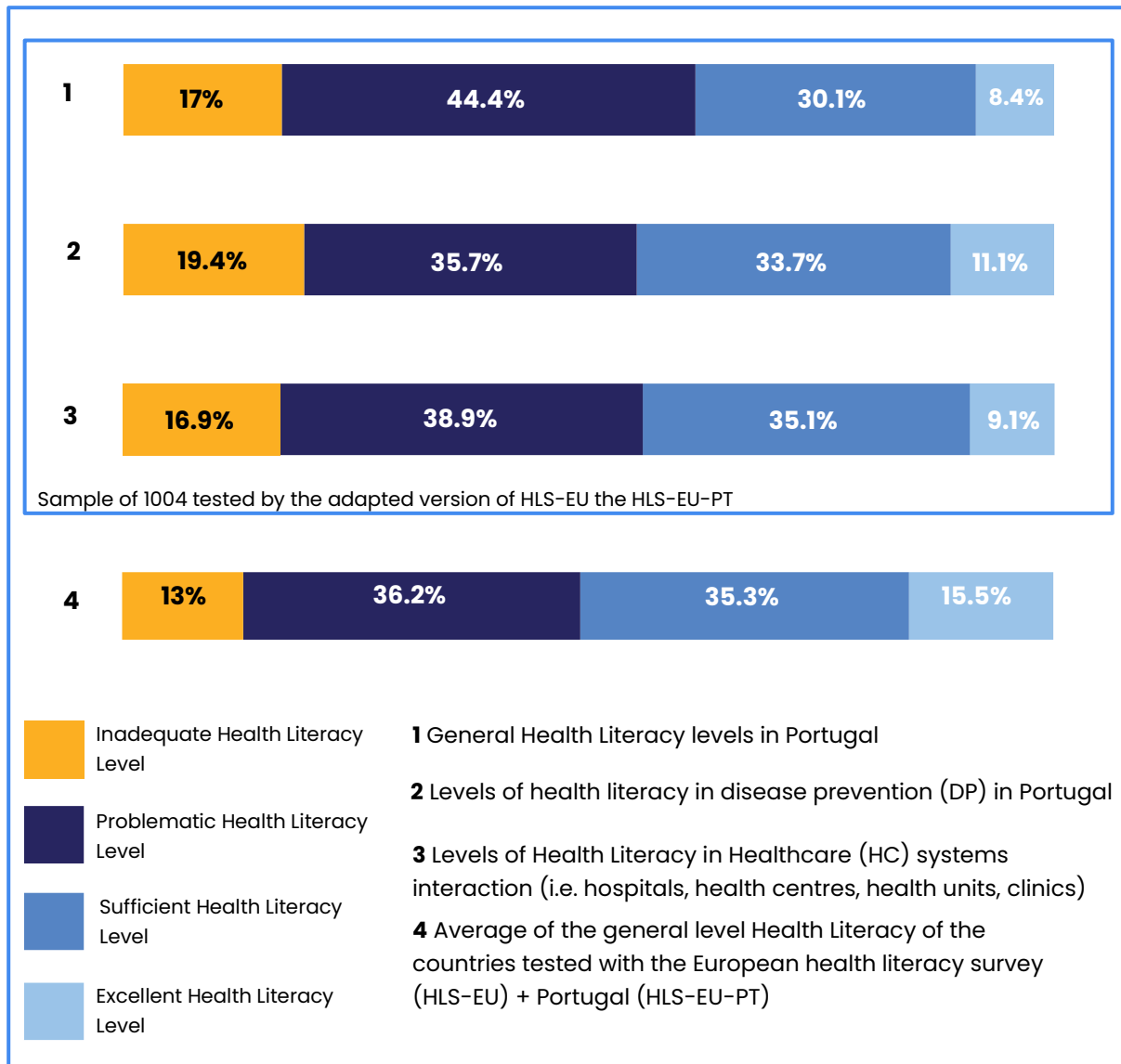


Figure 2. General health literacy levels, levels of health literacy in disease prevention (DP) and levels of health literacy in health care Systems interaction (HC) in Portugal. Average of the general level of health literacy of the countries tested with the European health literacy survey (HLS-EU) + Portugal (HLS-EU-PT). Adapted from (Pedro et al., 2016).

Chapter 4. Design Process and Methodologies

4.1. Design for Health and well-being

The World Health Organization's (WHO, 2024) defines health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity”.

Design for health and wellbeing is a field of research and practice that bridges the fields of design and health. The work of designers working in this field consists of applying their design knowledge to create new products, services, platforms and practices, or to optimise existing ones, in the prevention or support of disease, in providing medical care, in the performance of healthcare professionals and to increase health literacy, among others. This is an emerging area of specialisation with very specific characteristics that requires processes, methodologies and tools appropriate to this field. Such as the use of methodologies and processes from the field of Human-Centred Design, Participatory Design, Service Design or the use of techniques and tools for the scientific validation of results. According to (Ku & Lupton, 2020) “human-centred design involves observation, conversation, research and collaboration (...) the creative process involves asking questions, visualising ideas, creating tangible prototypes and telling stories about people, ideas and outcomes" (p. 10).

This is an emerging area with an important impact on the quality of life and well-being of all people.

4.2. Design Methodologies

As part of the development and implementation of the LISA cohort study to measure health literacy levels in the municipality of Leiria, as will be described in detail in the second part of the document, it was necessary to design a service - the operationalisation of the study in the field - through iterations of a design process centred on the needs of both the stakeholders, the LISA researchers, and its users, the adult population of Leiria.

To do this, it was necessary to use various design methodologies, such as the usability testing method to test the study questionnaire with a sample of the population (user group definition method). It was also necessary to develop workshops to define the profile of the interviewers, as well as using the persona creation method to define the team structure for the operationalisation of the study. An interviewer's manual was also created with scripts, guidelines and protocols for the interviewers to follow.

To publicise the study to the population and ensure that population participate, communication materials had to be developed. To do this, it was necessary firstly to research the materials and communication strategies used in other cohort studies by interviewing experts and, secondly to develop the brand and graphic identity of the LISA study and design the communication materials - flyers, posters, billboards, ID cards, T-shirts, participation cards, cards, websites.

The design methodologies used in the design process throughout the development of the cohort study are explained below.

4.2.1. Interviews

“Interviewing patients and other users is one of the most powerful tools in health design” (Ku & Lupton, 2020). Interviews are a qualitative research medium that allow the researchers to gain insight into the minds of the interviewees (Jacob & Furgerson, 2012; Ku & Lupton, 2020; Kumar, 2013; Marczyk et al., 2005; Marc; Stickdorn et al., 2018). They can be both formal and informal, the first has a preapproved script, the latter is more flexible and can have the flow of a normal conversation (Ku & Lupton, 2020).

4.2.2. Design Workshops

A design workshop can be carried out in a few hours or take up to several days, depending on the objectives and complexity of the project. These are very useful for bringing together multidisciplinary teams/groups (designers, specialists, end users, stakeholders) to reflect, explore and create creative solutions to a specific problem or challenge. A well-planned workshop can produce new ideas and help with decision-making. A workshop is a structured series of activities that encourages people to think creatively, share ideas and visualise them by drawing up graphics (using post-its, pens or markers for example), building simple prototypes and testing prototypes (IDEO, 2015).

Design workshops go beyond meetings to gain a deeper understanding of problems and collect authentic feedback. Meetings are usually dominated by a small group of "experts" and, as a result,

solutions are driven from the top down, whereas a workshop provides a safe space for a wide range of stakeholders to become active participants in the discussion of a problem. It is up to the facilitator, the person responsible for guiding participation, to ensure that everyone has an active role in the discussion.

According to (Ku & Lupton, 2020), workshop planning involves firstly defining the objective of the workshop very clearly, for example, designing a product or service, creating a profile of the interviewees, and so on. Then create an agenda, including time for introductions, activities and sharing. Set a time limit for each of the activities. Decide who will take part in the workshop (minimum of 6 participants). When trying to find, for example, a solution for a certain type of medical procedure, it's important to include people who suffer from that illness because they are the experts in identifying the concerns, pain points and frustrations of these procedures. To prepare the workshop, is also important to interview experts and real users previously to obtain information from their specialised knowledge.

4.2.3. Personas and User group definition

“A persona is a fictional character who represents potential users” (Ku & Lupton, 2020). Personas are the representative archetype of one person or a group of people. They can be used to personalize the design process to the end users (Engelhart & Moughamian, 1971; B. Ferreira, Silva, et al., 2015; B. M. Ferreira et al., 2016; Martin & Hanington, 2012; Miaskiewicz & Kozar, 2011; Petermans & Cain, n.d.). Personas can also be called user models (Cooper et al., 2014), this is

because of their potential to represent a group of people. They can represent the behaviours, habits, attitudes, aptitudes, goals, and motivations of the user being modelled (Cooper et al., 2014).

“For user-centred design, you need to understand people. However, attempting to design for everyone results in unfocused or incoherent solutions, so some level of consolidation is needed.” (Martin & Hanington, 2012). As mentioned, personas have the ability to define characteristics of user behaviour, and patterns of a group and turn them into an archetypal representation that defines said group (Martin & Hanington, 2012).

4.2.5. Usability Tests

Usability tests are an observational methodology used to find pain points and to improve a product with the participation of prospective users (Ku & Lupton, 2020; Moran, 2019; Nielsen, 2000).

“In a usability-testing session, a researcher (called a “facilitator” or a “moderator”) asks a participant to perform tasks, usually using one or more specific user interfaces. While the participant completes each task, the researcher observes the participant’s behaviour and listens for feedback.” (Moran, 2019). Usability-testing allows the researchers to understand the views of the users. How they will react and interact with the developed product (Ku & Lupton, 2020).

| Practical Project |

Chapter 5. Project development

5.1. The objective

This research aimed to use design knowledge and practices to aid in the development of the early stages of a cohort study that will take place in the county of Leiria.

The need to create this cohort study arose from the group (Leiria' City Hall and ACES Pinhal Litoral) that was developing the Strategic Health Plan (ACES Pinhal Litoral, 2019) for the municipality of Leiria, which revealed a high rate of metabolic diseases and comorbidities in the municipality of Leiria. In addition, there was also inadequate use of health services, with a large number of non-urgent cases going to the emergency services. There was therefore a suspicion that health literacy levels in this municipality were below the general national average. But as there was no data collection for this specific council (the existing data was only at national level), Leiria Municipal Council (CML) proposed the development of a study that could provide the missing data in the Local Health Plan.

The aims of this cohort are to monitor the lifestyle and health habits of the population in this area and possibly to relate those choices to the population's health literacy levels, proposing a connection between the knowledge one has about health and how this knowledge effectively affects lifestyle choices - leading to different levels of well-

being. Ultimately the study aims to improve the lifestyle of the population.

Therefore, the LISA study consists of a questionnaire for the population of Leiria containing six scientifically reviewed and validated surveys, namely:

- Socio-demographic characteristics and disease;
- FINDRISC – Finnish Diabetes Risk Score;
- HLS-EU-PT – Scale of health literacy assessment;
- FAGERSTROM – Test for Nicotine Dependence;
- HADS – Hospital Anxiety and Depression Scale;
- AUDIT – Alcohol Use Disorders Identification Test.

The development of this study is extremely important, as there is data indicating that health literacy levels in the municipality of Leiria may be below the national average, which is already below the European average (data collected from eight European countries, see chapter 3). As mentioned earlier in chapter 3 on health literacy, Portugal has a high number of people with a "problematic" and "inadequate" level of health literacy, specifically 61.4%.

5.2. Lisa Cohort

The study LISA is classified as a longitudinal observational study with a prospective nature (Hulley SB, Cummings SR), and initially aims to follow the adult population of the county of Leiria over the course of 4 years with intervals of approximately 2 years between observations (Figure 3) - this duration may be further extended to 10 years, depending on the stakeholder's intentions.



Figure 3. Representation of the time between observations. Made by author.

The stakeholders of LISA Study are ACES Pinhal Litoral, CiTech Care, the Hospital Centre of Leiria (CHL) and LIDA (Figure 4).

At the start of the study, the only stakeholders were the City Hall of Leiria and the doctors of ACES Pinhal Litoral. Then, the researchers from ciTechCare, the LIDA design team from the Polytechnic of Leiria and, finally the addition of nurses and doctors from the Hospital Centre of Leiria (CHL), joined the team, completing the multidisciplinary team that would develop the study.

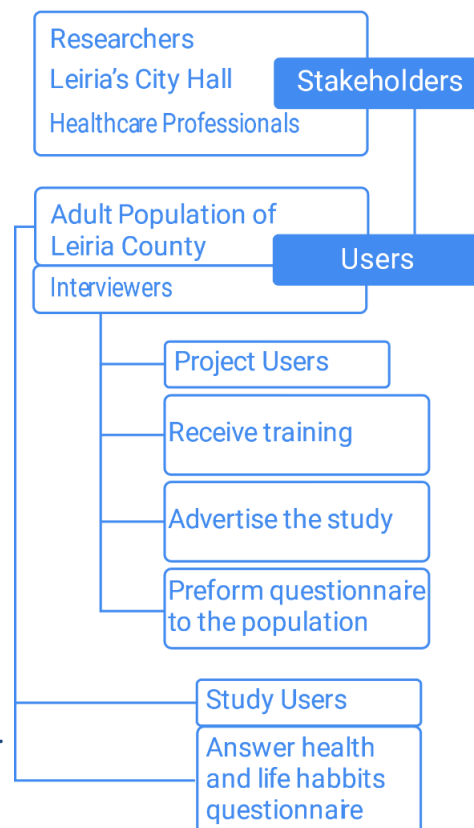


Figure 4. Representation of the initial LISA stakeholders and their objectives. Made by author.

The study was named LISA. This name was chosen from a list of multiple possible names because it has a connection with the city, recalling the River Lis (the river that runs through the city), and because the initials of the name of the study correspond to some of the elements of the study:

LI – *Literacia* (literacy);

SA – *Saúde* (health);

Lis – The city's river.

5.3. Study development team

As mentioned above, to carry out the study, a multidisciplinary team, Figure 5, was initially set up with members from ACES Pinhal Litoral, the CiTech Care - Centre for Innovative Care and Health Technology research unit and CML. This team was later expanded to include designers from the LIDA - Laboratory in Design and Arts research unit and nurses and doctors from the Hospital Centre of Leiria (CHL),

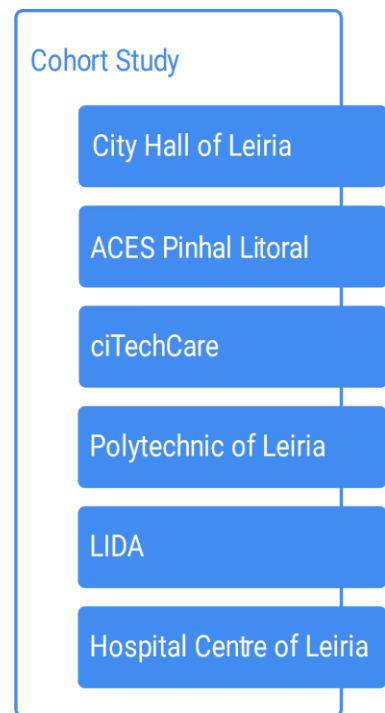


Figure 5. Representation of the final LISA development and stakeholder team. Made by author.

The design team was composed by two master students, myself (Constança Rocha) and Daniela Marques, from the Master's programme in Design for Health and Well-being (School of Art and Design, Caldas da Rainha) and assistant researchers from LIDA who worked under the supervision of professors and integrated members, Elga Ferreira e Eliana Penedos-Santiago, of the same school and research unit.

Part of the work was carried out jointly by the two students, but tasks were also carried out individually. These tasks, materials and documents will be explained in detail in the following sections. Below are the lists of tasks carried out jointly and by each student:

Tasks, materials and documents developed by the two students, myself (Constança Rocha) and Daniela Marques:

- Interviews with experts working on other cohort studies;
- Testing the study's surveys with representatives of the population of the municipality of Leiria;
- User groups definition map;
- Moderation of the Green and Red Feedback Workshop, to define the interviewers' personas - workshop designed by Daniela Marques and moderated by Constança Rocha;
- Definition of the LISA Cohort Study brand - Name, colour palette, icons, study signature, study's catch phrase and logo;
- Guidelines for implementing a cohort study;
- Interviewer's manual.

Tasks, materials and documents developed by me (Constança Rocha):

- Definition of interviewer, team leader and supervisor personas;
- Website interface design;
- Design of the study's page housed in the City Hall's website;
- Design of the study's informative graphic content to be integrated both into the CML website and the study's website.

Tasks, materials and documents developed by student Daniela Marques:

- Workshops to define the service blueprint - workshop design and moderation;
- Workshops to validate the developed personas - workshop design;

- Service Blueprint for the study (document);
- Design of printed materials - leaflets, posters, T-shirts, roll ups, Muppis, billboards.

5.4. Study structure

The goal of the design team's work was to develop effective communication of the study to the population and to attract participants.

At the beginning of the development of the cohort study, the main stakeholders and researchers began by defining that the form of data collection would be a questionnaire (Appendix H). One of the main questions in developing a cohort study is how to carry out this questionnaire, by telephone, e-mail, letter or in person. This was one of the first tasks assigned to the designers after they joined the multidisciplinary team. This task consisted of understanding the pros and cons of the different methods available.

To this end, the design team interviewed experts who had worked on other cohort studies (these interviews will be explained in detail below). According to these experts, in order for the study to get off to a more successful start, then a more empathetic (Calvo & Peters, 2014; Ku & Lupton, 2020) method was required, therefore the door-to-door (face-to-face) questionnaire method. This option allows for a more personal connection with the study, since people create empathy more easily if they have another person in front of them (Calvo & Peters, 2014; Hulley et al., 2007; Ku & Lupton, 2020), unlike a

telephone approach, where empathy is much more difficult to establish.

To use this method, it was identified the need to select interviewers and train them, since they would be the centrepiece of the study, as they would be the direct link between the study and its participants.

5.5. Project design methodologies

As mentioned before, the role of the methodologies used was to be successful in putting the study into practice and prioritising the needs of the stakeholders and interviewees. Although the end users of the study are the study participants, the users also include chosen interviewers and the stakeholders (Figure 6).

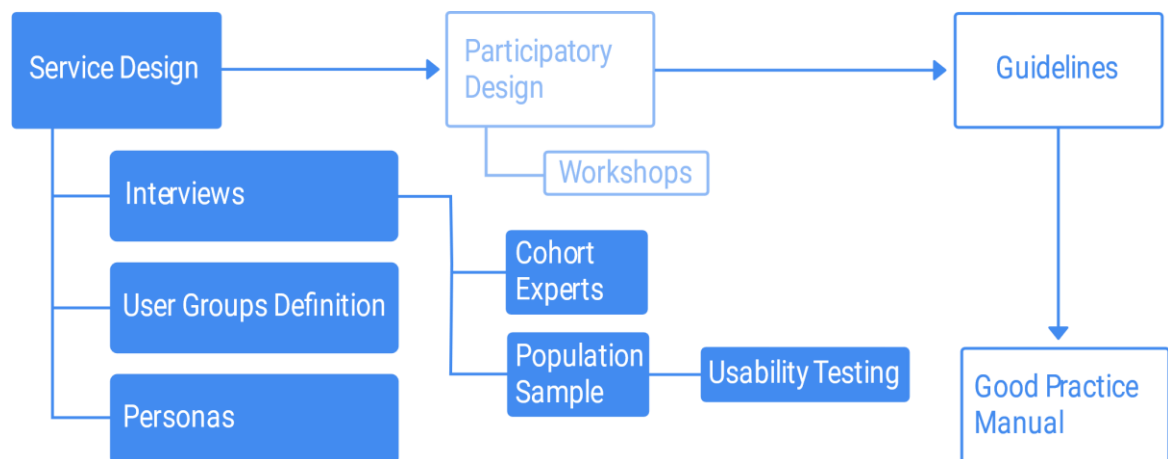


Figure 6. Representation of the design method chosen by the designers with a focus (blue) on the methodologies used first. Made by author.

The choice of the used methodologies arose organically with the development of the project, through meetings with the multidisciplinary team. At these meetings, the team discuss the best

strategies to apply when developing the different tasks. This effort enabled the design team to select the most appropriate methodologies for the project.

5.6. First challenge: Finding the role of the Designer

As already mentioned, at the beginning of the study, the role of the designer in a project of this kind was blurry, as it had not yet been defined by precedent. To this end, several meetings and interviews were held with the stakeholders to determine what that role would be. At first, this process proved challenging due to preconceived notions about what a designer could do and bring to the project. Through these meetings and interviews, the designers were able to assess the expectations of the stakeholders and inform and clarify them about what a designer specialising in the health area could offer. The result of this process was the decision that in the study, in addition to developing the image and the communication of the study, the proposed role of the designer would be to design the tools and materials to support the selection and training of the interviewers and to design the study's operation and structure. To do this, the designers would have to devise a way to give the interviewers the necessary skills to communicate and relate to the population, considering the different backgrounds and how these can affect the opinions the population has about the study. To prepare the selected interviewers for the different realities they might

encounter in their contact with the end users (the adult population of the county of Leiria), in Figure 7 the first sketch of the designer’s proposed role can be seen.

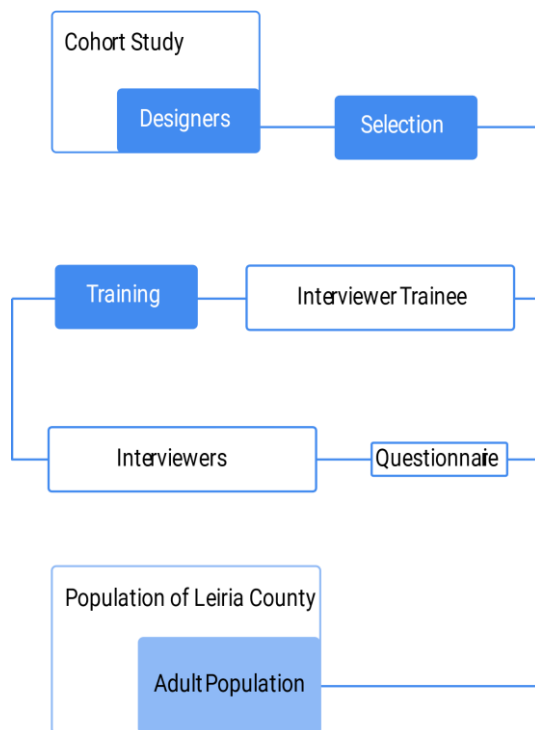


Figure 7. Initial sketch of the possible designer contribution. Made by author.

5.7. Design Process

As mentioned earlier, the design process in this study took place simultaneously with the development of the study itself. This allowed the process to grow more organically and achieve greater final solidity.

5.7.1. How it began

The first step in the design process was to identify and define the research questions. Initially, there were several questions, some about how a designer could fit into a study of this nature, others related to how to communicate the study to the population, and others about how design domain could help the stakeholders to have a more solid connection with the study's target audience. In the end, the research questions identified were:

- How can a designer specialising in the health area become an integral part of a multidisciplinary team? And how can we communicate what Health Design is to the stakeholders?
- How can design processes optimise the development, implementation and progress of this cohort study? How and how important is it for the design field to intervene in the early stages of a cohort study and not just be responsible for developing the study's communication to the population?
- What design methodologies and materials could be used to select and train the interviewers who would interview the population?

The first question “How can a designer specialising in Health become an integral part of a multidisciplinary team? And how can we communicate what Health Design is to the stakeholders?” was identified during the first meeting with the stakeholders. It was possible to realise the difference in expectations between the designers and the stakeholders. This arose from the need to communicate how we, as designers, would communicate our role to

the stakeholders and show that a designer should be an integral part of the study from the very beginning of its development.

The second question, “How can design processes optimise the development and progress of this cohort study? How and how important is it for the design field to intervene in the early stages of a LISA cohort study and not just be responsible for developing the study's communication to the population?” arose from the need for a critical analysis of how design can intervene in the different phases of the development of a cohort study.

Leading into the final question: “What design methodologies and materials could be used to select and train the interviewers who would interview the population?” Which reflects on what design methodologies and materials should be used to select and train interviewers to communicate effectively with the target population. These questions were formulated and refined as the meetings with the stakeholders were taking place.

5.7.2. What it became

A process was developed within the scope of Service Design (Kumar, 2013; Morelli et al., 2021; Marc Stickdorn et al., 2017) and Communication Design (Aakhus, 2007; Garrett, 2003; Kumar, 2013), supported by Participatory Design (Calvo & Peters, 2014; Ku & Lupton, 2020; Kumar, 2013). Different design methodologies and tools were used in the process of developing the study. The first part of the process was based on understanding the needs and expectations of the different types of users of this project. The second, consisted of

developing the study's brand and materials for communicating and advertising the study to the community, and finally, the third part of the process focused on defining the interviewer profile to be used in the selection process and developing training materials for these selected interviewers.

5.8. Design Methodologies

As mentioned above, the design methodologies and tools used consisted of interviews with experts who have worked on other cohorts, interviews and usability tests with a sample of the population and workshops to define user groups and create personas. In addition, strategies and tools from the field of Communication Design were used to develop the study's brand and communication materials. This process model can be seen in Figure 8.

maintain them over the years, to confirm that a sample of the population had a good understanding of the questionnaire, what the ideal profile of interviewers should be, prepare the materials for their training and to develop the design of the service.

These meetings were crucial for the multidisciplinary team's communication, helping to understand all the team's points of view. Thanks to them, the designers' expected contribution was extended to the different development phases of the study.

5.8.2. Interviews

In the beginning of the study due to the intervention of the designers, two sets of interviews were planned, one with experts in cohort studies, people who had already participated in the development of successful cohort studies in Portugal, and another, interviews with a sample of the population. The first set of interviews aimed to help designers and stakeholders understand what the main barriers and challenges were in planning a cohort study, and what they had done to overcome these challenges. The second set of interviews aimed to convey to the stakeholders and the multidisciplinary team what the population's expectations might be when faced with a study of this nature and what would make the population want to participate and stay in the study throughout its duration.

5.8.2.1. Interviews with the experts

The first set of interviews began with an interview with one of the members of the study's research team and a member of CiTech Care. This interview (Table 1) was the first to take place since the interviewee already had experience in other cohorts and was a member of the multidisciplinary team. In this interview, the designers' focus was to understand what stage the study was in, what the plans were for it and what expectations the team had for the study itself. This interview was a little different from the ones conducted with the other experts, because it not only asked the expert in question about his experience in other cohorts, but also about how this specific LISA cohort was being planned, and the questions were as follows:

Table 1. The planned set of questions used in the first interview with an expert. Made by author.

Questions

- What is the relevance of this cohort study for the city of Leiria?
- What is the process for starting the study?
- What name could we give the cohort study, so that it would be known by the population?
- How would you define the preparatory phase of this cohort study?
- In the cohort studies in which you have participated in, how has communication been addressed?
- In relation to previous cohort projects, in what ways did you approach the population?
- And how did you maintain their interest in the project?

-
- What was the drop-out rate in similar cohort projects?
 - What gaps were identified in the cohort studies in which you participated?
 - You don't plan to talk to 16-year-olds as they will later be part of the +18 population?

From this interview the designers were able to create a level playing field, where they could be aware of what was already happening and what still had to be done and projected.

As the conversation progressed, this interview also gave a better understanding of the importance of the study and the relationship between the data collected and the population's health literacy knowledge and lifestyle choices (i.e. smoking habits, alcohol consumption habits, health monitoring). This allowed the researchers to investigate the possible correlation between them, since there was no specific data from the Leiria area to make this connection (ACES Pinhal Litoral, 2019).

Another important fact that emerged from this interview was that, on average, 40% of participants are lost from one phase of the study to the next. This made the team realise that there needed to be some kind of strategy to keep participants affiliated with the study.

The remaining experts (Table 2) were then interviewed (Table 3). Due to geographical limitations and the Covid-19 pandemic, all these interviews were conducted via videoconference (online), and it was not possible to complete the incomplete interview due to unforeseen circumstances.

Table 2. Interviewed experts. Made by author.

Expert	Affiliation	Cohort Studies	Duration (min)
Sara Dias 10/11/21	School of Health Sciences, Polytechnic of Leiria, Leiria, Portugal Center for Innovative Care and Health Technology (ciTechCare), Polytechnic of Leiria, Leiria, Portugal	- EpiDoC- The Epidemiology of Chronic Diseases Cohort - LISA – Longitudinal Study in Health Literacy in Leiria’s county	63
Carla Lopes 17/11/21	Epidemiology Research Unit (EPIUnit), Medical School of University of Porto	- EPIPorto cohort - EPITeen – Epidemiological Health Investigation of Teenagers in Porto - Generation XXI cohort	62
Helena Canhão 15/12/21	EpiDoC Unit, CEDOC – Center for Chronic Disease Studies NOVA Medical School / Faculty of Medical Sciences CHRC Comprehensive Health Research Center	- EpiDoC- The Epidemiology of Chronic Diseases Cohort - EpiReumaPt Project	15 (incomplete)
Ana Rodrigues 26/01/22	EpiDoC Unit, CEDOC – Center for Chronic Disease Studies NOVA Medical School / Faculty of Medical Sciences CHRC Comprehensive Health Research Center	- EpiDoC- The Epidemiology of Chronic Diseases Cohort - EpiReumaPt Project	52

Table 3. Planned questions used in the experts' interviews. Made by author.

Subject	Questions
Introduction	Hello, we are here on behalf of a cohort study that will take place in the county of Leiria with the aim of measuring the literacy levels of the population. As planned, we are here to ask you some questions related to cohort studies to understand what the most common challenges and problems are.
Previous cohort experience	<ul style="list-style-type: none"> - How many cohort studies have you been in? - What are the beginning processes of a study of this nature? - In the cohort studies you've been in, how was the communication conducted? - What communication materials were used? - How did you approach the population? - Is there a contact approach that produces better results? (phone, letter, or door-to-door) - How many people did you have to approach to get the desired sample size? - In what way did you try to keep the participants motivated in the study? - What was the abandonment rate in the projects you've been a part of? - What were the common issues you've found? - Did you have a preselection process for the interviewers? - What type of personality is better to work door-to-door? - How did the teams work in the field?

The set of interviews carried out with other cohort experts was done with the aim of understanding what had already been done in the country, how it was done and, most importantly for our purposes, what some of the challenges were that occurred in these studies.

From these interviews, it was understood that the main concerns that LISA would face were going to be the gathering of participants, the ability to keep these participants motivated and engaged in the study to avoid loss to follow up, and the ability to build a team that could sustain the study throughout its duration. As the interviews went on, the designers noticed that the same challenges identified kept being mentioned by various experts, so a list was compiled (see “*Final considerations from the interviews*” section).

5.8.1.2. Interviews with the population

The population sample was the second group to be interviewed (Figure 9). The designers informed the stakeholders of the need for early contact with members of the Leiria population. The interviewees were chosen for their diversity in terms of age, education and area of residence (Table 4). Due to the Covid-19 pandemic, most of these interviews were conducted by videoconference.



Figure 9. Photos taken during the interviews to the population sample. Dias, S. 2021.

Table 4. Interviewees description. Made by author.

ID & Date	Age	Gender	Geographic Placement	Education Level	Session
Int 01 15/12/21	78	Female	Village	4 th grade	Presential
Int 02 15/12/21	22	Male	Village	Bachelor's Degree	Presential
Int 03 15/12/21	55	Female	City	12 th grade	Presential
Int 04 21/12/21	24	Female	City	Master's Degree	Online
Int 05 21/12/21	24	Male	Outskirts	TESP (professional higher technical course)	Online
Int 06 14/01/22	62	Female	Village	6 th grade	Online
Int 07 19/01/22	43	Female	Outskirts	12 th grade	Online
Int 08 19/01/22	41	Male	City	PhD	Online

At the beginning of each of these interviews the designers presented the interviewees with an informed consent form (Attachment I) due to the possibility of sensitive data being shared during the conversation. In the case of the online interviews, this form was signed by the interviewee and then forwarded by email.

In these interviews (Table 5) a part of the population was able to test the questionnaire (Attachment H), these people were then asked to react to the questionnaire as they filled it out.

Table 5. Interviews to the sample population. Made by author.

Subject	Questions
Introduction	Hello, we are here on behalf of a cohort study that will take place in the county of Leiria. Since you are a representative of a part of the population of Leiria, we would like to ask you some questions concerning the study. Your data will be used only for the study, and the process will be in the designers' dissertations. We ask you to read and sign the Informed Consent if you agree with its contents.
Demographics	<ul style="list-style-type: none"> - What is your age? - What is your gender? - What is your education level? - Where is your place of residency? (city, outskirts or village) - Can you give us your contact in case we need to reach you again? (e-mail, phone number)
Health Literacy	<ul style="list-style-type: none"> - Do you know what health literacy is? (if the answer is no, we will explain what it is) - What do you think your health literacy level is, from 0 to 5? (0 is low 5 is high) - Would you like to increase it? - In what way do you think you could increase your health literacy level?
Cohort Study	- Do you know what a cohort study is? (explain what LISA cohort study is and what it proposes to do)

-
- Do you believe a study of this nature is important for the population?
 - Would you be interested and available to participate in a cohort study?
 - What would motivate you to participate in it?
 - Where would you look to find information about this study?
 - In what way do you think this study should be advertised?
 - What would be the best places for the communication of the study? (hospitals, health centres, social media, etc.)
 - How would you prefer to be contacted by the study? (phone, letter, door-to-door)
 - What would be the best schedule to reach you? (if the preferred contact was by phone or door-to-door)
 - Would you be comfortable if the contact was at a late hour? (end of the afternoon)
 - In LISA cohort study, the contact will be done door-to-door, how many people should do the contact?
 - What is the appearance of a person you wouldn't mind opening your door to?
 - Would you be available to go to a different place to take part in the study? (health care center, health units, etc.)
 - Would the possibility of performing routine exams increase the likelihood of your participation in the study?
 - What would it take for you to remain in the study throughout its phases?
 - What rewards would you like to receive for being an active participant of this cohort study?
-

The combined information from both sets of interviews allowed the completion of the list of probable pain points and challenges to the study (presented in the next section).

5.8.2.3. Final considerations from the interviews

After all the interviews with the experts and the sample population were completed, the multidisciplinary team asked the designers to compile a list of challenges (Table 6) with the information gathered in the interviews, to which the designers also added a section with their own assumptions. This compilation of information also served the purpose of making the information more readily available (D. S. F. Marques & Netto-Rocha, n.d.), (Appendix D).

This list is an outcome of this research (and Daniela Marques) as it will serve as a reference for future research in this area and as a guide for the development of future cohort studies.

Table 6. Challenges and Assumptions compilation. Made by author.

Challenges/Assumptions
- Raise participants, no matter the method of contact – door-to-door, phone calls, letter, etc;
- Adapt the follow-up method in the following phases – door-to-door, phone calls, letter, etc;
- Ensure participants and interviewers safety – avoid scams, robberies, etc;
- Keep the population motivated to keep participating;
- Keep the field team committed to the study;
- Capacitate the field team to communicate with the population;
- Provide continuous training to the field team;
- Hire a supervisor and someone with Backoffice knowhow;

- Decide where the questionnaire will be held – participant’s house, units prepared for the study;
- Questionnaire method – read by the interviewer and filled out by participant, read and answered by the interviewers with the information given by the participant;
- Questionnaire format and plan B – paper, digital;
- Participants understanding the need for such an extensive questionnaire;
- Communication methods to be used – posters, flyers, outdoors, advertisements, etc;
- Determine where the communication will be held – city, outskirts, villages, rural areas;
- Defining the channels for communicating the study – hospitals, health units, coffees, churches, etc.

Expert insight

- Clear identification of interviewers when approaching the population – badge, identifiable t-shirt, ID card;
- Have funding to ensure the operational team is paid to promote motivation;
- Give compensation to participants to keep them engaged with the study– some rewards such as discounts in coffees associated with the study;
- Provide training to the team in the field;
- Use physical communication to build trust in the study – flyers, posters, outdoors, etc;
- Give participants feedback on the study to keep them motivated;
- All entities involved must be kept informed so there are no miscommunication and conflicting information;
- Have someone working specifically in Backoffice;
- Have an interviewer’s handbook;

- Understand there is a considerable drop in participants at each interval of the study;
- There is a higher success rate in raising participants door-to-door than by phone;
- Keep in mind that to raise X participants it is necessary to go to 10X doors;
- Keep interview time to a maximum of 30 minutes when in person, and to 15 minutes when by phone.

Population Insight

- Most of the population doesn't know the term cohort, or what a cohort study is;
- The population needs to be more motivated to obtain more knowledge regarding health;
- The population prefers the first contact to be made by phone or e-mail;
- The communication should be done on social media and in healthcare facilities and affluent places of the region – coffee shops, pharmacies, etc;
- The preferable contact time is in the evening before dinner, especially on Saturday afternoons;
- The majority of the people interviewed would accept to commute, if their participation does not overlap with working hours;
- If there is a need for a commute, there is the need to compensate the participants, for example by offering them routine health tests;
- Give study feedback to the population, on how their participation impacts the study;
- The building types can hinder the door-to-door process;
- There may be initial suspicion when the first contact is made door-to-door;

- Identify the ideal compensation/rewards for participating in the study – discounts to enter cultural events, free parking in the city centre, coupons to use in local stores, etc.

5.8.3. User Groups Definition

The User Groups method was used to understand the distribution of the adult population of the county of Leiria. The population was divided and organized according to age, gender, level of education and place of residence. Initially the designers made a map (Figure 10) with their assumptions about what this distribution might be:

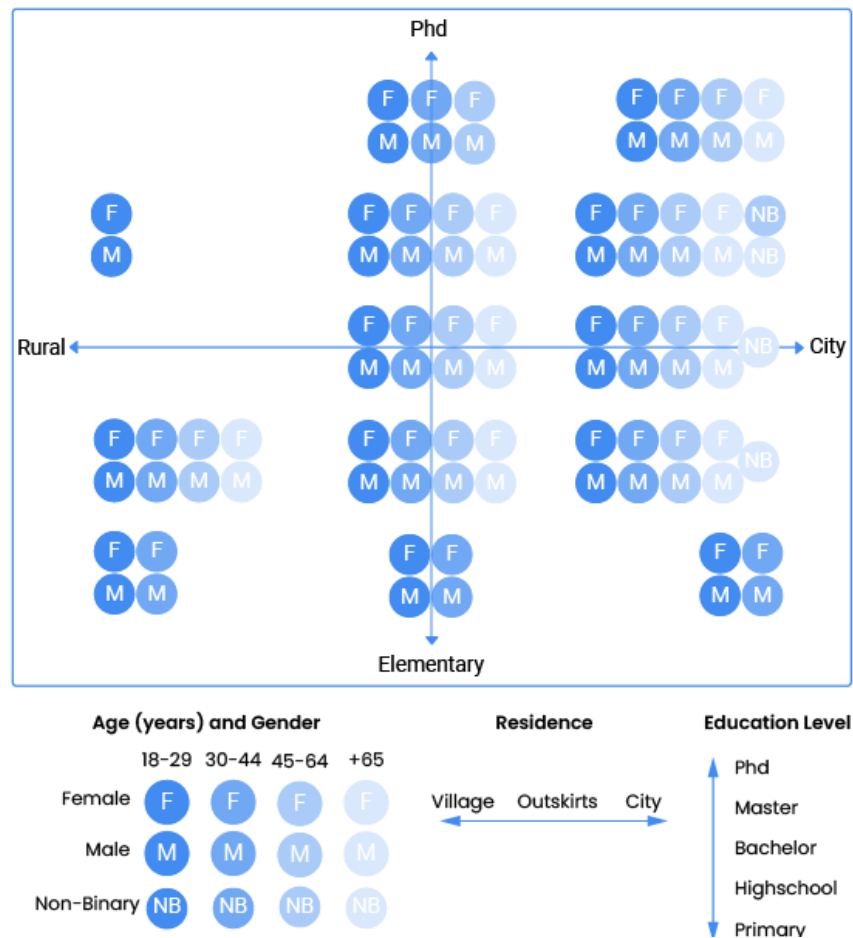


Figure 10. Map of the assumed sample population distribution. Netto-Rocha, C. Marques, S. 2022.

The figure above is a qualitative adaptation based on the demographic graphs of LISA study and assumptions about the geographic distribution of the population, is purely qualitative since the specific data is sensitive. It is also important to note that this distribution assumption only considers possible participants in LISA (Table 7).

Table 7. Sample needed for the validity of the study. Adapted from the study's documents.

		Participants	
		Female	Male
Age (years)	18-29	665	665
	30-64	670	670
	65+	667	665
	Total	2002	2000

This assumption (Figure 10) was then shown to the interviewed population sample and, through their input, the map was altered to represent what the interviewees felt was a more accurate representation of their reality (Figure 11). Considering the sample was very reduced, the validity of this map isn't high, however it allowed the team to have a better understanding of what people thought about their surroundings.

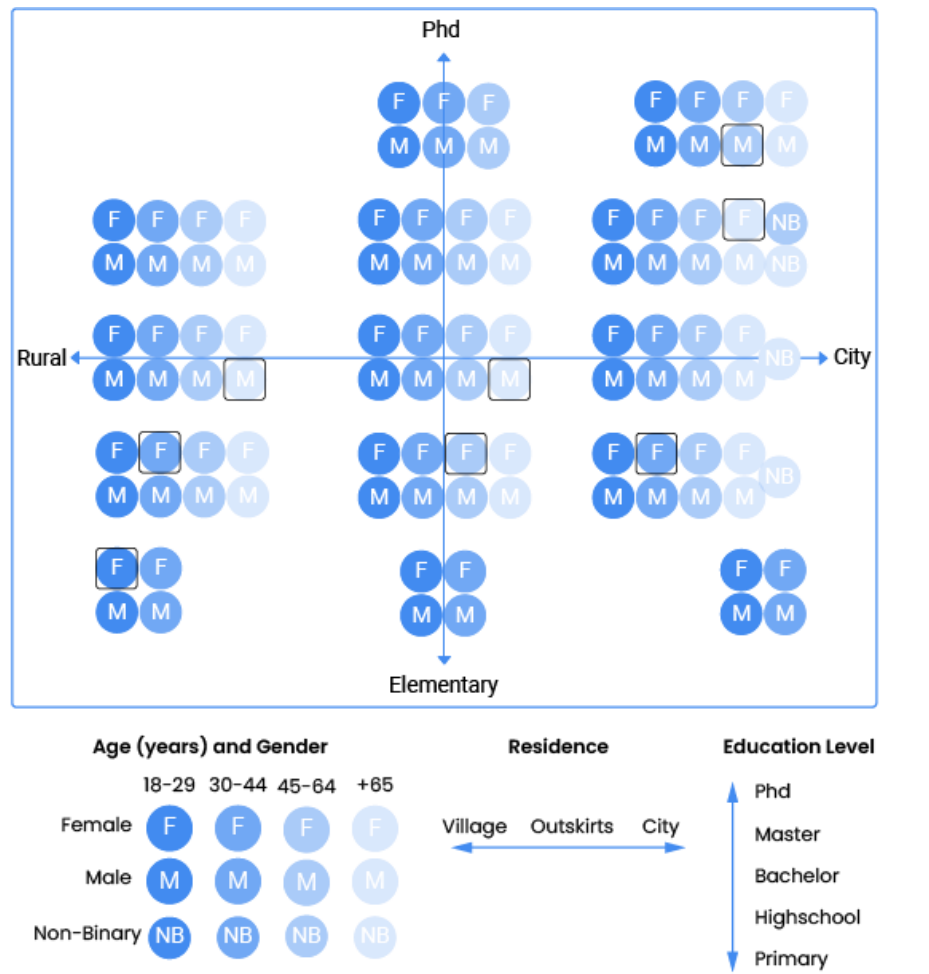


Figure 11. Finalized Population Distribution. Netto-Rocha, C. Marques, S. 2022.

5.8.4. Usability Testing

In order to test the understanding of the study questionnaires among representatives of the population of the municipality of Leiria the designers carried out usability tests. (Moran, 2019; Nielsen, 2000) These usability tests took place in person and during these tests,

the interviewees were asked to fill in and react to the digital questionnaire and the designers took note of the reactions and doubts that arose.

As mentioned before, the questionnaire used in the LISA study contains six surveys with scientific review and validation, they are:

- Socio-demographic characteristics and disease;
- FINDRISC – Finnish Diabetes Risk Score;
- HLS-EU-PT – Scale of health literacy assessment;
- FAGERSTROM – Test for Nicotine Dependence;
- HADS – Hospital Anxiety and Depression Scale;
- AUDIT – Alcohol Use Disorders Identification Test.

Each one of these six surveys has already been scientifically validated, so it wasn't possible to make any major changes to the questions, as this would divert them from the objectives of the study and compromise their validation.

With the data collected on the same questions and difficulties in filling out the questionnaire, some minor formatting and wording changes were possible. Below (Table 8) are the insights gathered from the users who tested the questionnaire.

Table 8. Population usability tests. Made by author.

ID & Date	Age (years)	Digital Literacy (Self-assessment)	Difficulties Found	Time (min)
User 01 15/11/21	47	High	<ul style="list-style-type: none"> • Misleading Layout in some questions; • Need additional information; • Similar and repetitive questions cause confusion. 	48
User 02 01/12/21	18	Medium	<ul style="list-style-type: none"> • Certain questions are meaningless; • Prefers to read the questions aloud to understand them better; • Answers without reading the information section. 	27
User 03 15/12/21	67	Medium - Low	<ul style="list-style-type: none"> • Misleading Layout in some questions; • Unclear and confusing questions; • Challenges in using various electronic devices. 	29
Int 01 15/12/21	78	Low	<ul style="list-style-type: none"> • Need for assistance filling out the survey; • Misunderstands the meaning of the questions; • Need additional information. 	26
Int 02 15/12/21	22	Medium -High	<ul style="list-style-type: none"> • Unclear and confusing questions; • Health skills help to understand the survey; • Prefers to read and fill out the survey. 	20
Int 03 15/12/21	55	Medium	<ul style="list-style-type: none"> • Lack of focus when answering the questionnaire; • Need for additional information; • Prefer that someone else reads the questionnaire. 	50
Int 04 15/12/21	24	High	<ul style="list-style-type: none"> • Unclear and confusing questions; • Many answers depend on previous experience; • Prefers that someone else reads the questionnaire. 	20

The table above (Table 8) shows the two sets of usability tests carried out on the questionnaire. The first set (user 1, 2 and 3) consists of a general test of the original, unchanged questionnaire. This set was carried out to allow the designers to familiarise themselves with the questionnaire and its possible pain points. The testers in this group were not residents of Leiria. After this set of tests, some minor formatting changes were made.

The second set of usability tests was carried out by some of the members of the population sample (Int 01, 02, 03 and 05). Not all of them were able to complete the questionnaire due to time constraints. In this set of tests, the main goal was to understand the best method of filling out the questionnaire, printed or on a tablet, filled out by the interviewee, or filled in by the interviewer. After carrying out the tests, it was decided that to minimise doubts and mistakes, it would be best for the interviewer to read the questions aloud and then fill them out with the answers given by the interviewees. This method would also allow for a standardised process, considering that all the participants would have the same experience.

Initially, it was planned to have at least 5 people answer and fill out the questionnaire to fulfil Jacob Nielsen's requirements. According to (Nielsen, 2000) almost all pain points can be detected using five testers.

The usability tests brought to light various issues with the questionnaire, from being confusing to difficult to fill out.

Some of these issues were communicated to the multidisciplinary team and solved, but because this questionnaire is a scientifically

validated instrument, not all the issues identified could be addressed. It should be noted that, months after this questionnaire testing phase, a new (shorter) validated questionnaire on health literacy in Portugal appeared, so some parts of the tested questionnaire are different from those of the questionnaire used later in the study.

5.8.5. Brand Design

The development of the study's image and brand was one of the designers' main focuses, given the importance of communicating the study to the population. The designers began by meeting with the stakeholders and asking them if they already had a name in mind. It turned out that most of the stakeholders had the idea of calling the study LISA.

This name was then chosen because it is linked to the city where the study is taking place and is reminiscent of the river that runs and crosses the city, Lis. The name was also thought of because, as previously mentioned, LI for *Literacia* (literacy) and SA for *Saúde* (health).

The designers began their task of developing the study's face and brand, starting with the choice of colour pallet. Initially, the designers asked the public health doctors in the study's multidisciplinary team what colour represented the medicine course in Portugal, and the answer was yellow. So, it was decided what the first accent colour for the study's pallet would be. Then, to represent the researchers a dark blue was chosen as it has ties to the course of Documentation and Information Sciences. Once these two colours had been chosen, the

designers began to make combinations (Figure 12) with them and possible palettes.



Figure 12. Different colour combinations. Netto-Rocha, C. Marques, S. 2021.

The palette chosen presented in (Figure 13), with two more blues was chosen because of its ability to harmonise colours and because these two new blues represented the waters of the River Lis.



Figure 13. Final colour palette. Netto-Rocha, C. Marques, S. 2021

Simultaneously, the designers were in the process of choosing the typeface to be used in the study. Several fonts with a free commercial licence were selected (Figure 14). Only two were chosen, one with serifs, "Source Serif Pro" - chosen for its legibility, which would be used in printed documents and in the study's signature - and another sans serif font, "Poppins" - chosen for its clean style, to be used in titles and in the lower case in the logo.

Roboto - Frase de experiência
 Montserrat - Frase de experiência
 Lato - Frase de experiência
 Poppins - Frase de experiência
 Ubuntu - Frase de experiência
 Nunito - Frase de experiência
 Titillium Web - Frase de experiência
 Barlow - Frase de experiência
 Inconsolata - Frase de experiência
 Dosis - Frase de experiência
 Source Serif - Frase de experiência
 Poiret One - LiSa LISA Lisa
BEBAS NEUE - LISA LISA LISA
 CINZEL DECORATIVE - LISA LISA LISA LISA
 Josefin Sans - LiSa LISA Lisa lisa
 Amiko - LiSa LISA Lisa lisa
Signika - LiSa LISA Lisa lisa
 Philosopher - LiSa LISA Lisa lisa
Poppins - LiSa LISA Lisa lisa
Source Serif - Frase de experiência

Figure 14. Fonts considered and chosen for the study.
 Netto-Rocha, C. Marques, S. 2021.

The next stage was to develop the study's logo. The designers began looking for references of logos from similar studies (Figure 15) and city entities (Figure 16).



Figure 15. Logos from similar cohort studies. Netto-Rocha, C. Marques, S. 2021



Figure 16. Logos from city entities. Netto-Rocha, C. Marques, S. 2021

The designers also searched for symbolic elements of the city of Leiria, to create a greater connection between the study and the city. From this search, the designers began to idealise possible symbols for the study's logo. The main symbols chosen were the centre of Leiria's main square, square "Praça Rodrigues Lobo", the details from the ceiling of the city's old cathedral and the balcony arches of Leiria's Castle (Figure 17). Then, several sketches were made for the logo, as can be seen in the image below (Figure 18).

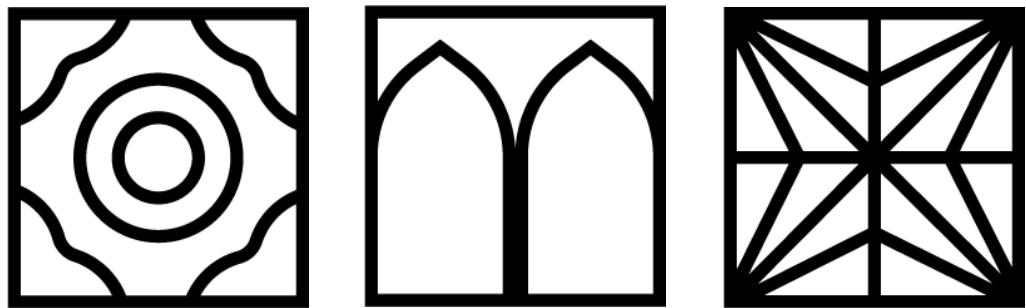


Figure 17. Main symbols chosen. Netto-Rocha, C. Marques, S. 2021

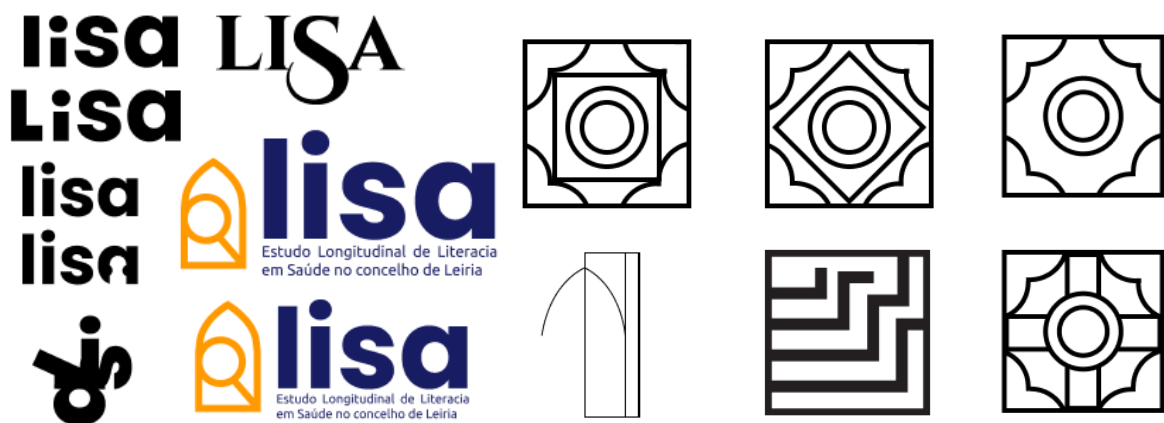


Figure 18. Logo and symbols sketches. Netto-Rocha, C. Marques, S. 2021.

After finalising these symbols, the designers noted that they could be used as a tile pattern, opening up the possibility of using them to recall traditional Portuguese tilework.

The final logos (Figure 19, 20) were created from symbolic icons of the city of Leiria, as mentioned above, because they create a solid link between the study and the city of Leiria. They also allow a flexible use, as they are interchangeable and make it possible to play with the different colours in the palette. When creating the logos, the designers also created the study's signature - *Estudo Longitudinal de Literacia em Saúde no Concelho de Leiria* - and the study's catch phrase on the communication material the slogan - *Saber Ser Saúde*.



Figure 19. Final logo and its variations. Netto-Rocha, C. Marques, S. 2021.



Figure 20. Final logo and it's variations with the study's signature. Netto-Rocha, C. Marques, S. 2021.

5.8.6. Communication materials

Once the development of the logo was complete, the process of developing other communication materials began. The designers began by identifying which communication media were most appropriate for communicating the study to the population. The focus was digital formats, websites (study website and section on the Leiria City Council website), as well as physical formats, flyers, posters, billboards, etc. The development of these materials was

divided between the two students of the design team, one of whom, me (Constança Rocha), focussed on digital, and the other student, Daniela Marques, on physical communication formats (Attachment C). The detailed explanation of the development of the website will be presented later.

However, it was also necessary to develop a budget (Table 9), for which the whole stakeholder team collaborated. This budget would include the costs of producing the communication materials, as well as other operational costs.

Table 9. Communication materials budget planning. Netto-Rocha, C. Marques, S. 2021.

Material	Description	No.	Unit Price	Total
Flyers	“munken lynx” paper, SRA5, medium-low (gram), full colour, double-sided printing	40 000	---	---
T-shirts	Logo imprint (10x10) on the left side – 2 for each interviewer	64	---	---
ID Cards	Laminated paper, 8x5 cm	50	---	---
Posters (A3)	Medium-low (gram), A3, full colour, one-sided printing	150	---	---
Posters (A4)	Medium-low (gram), A4, full colour, one-sided printing	350	---	---
Letters	Printing of the LISA logo and organising institutions logos, letter has information on the study	10 000	---	---
Envelopes	Printing of the LISA logo and organising institutions logos	10 000	---	---

Participation Card	8x5 cm, medium-high (gram), full colour, double-sided printing	8 000	---	---
Muppis	Adaptable size, full colour, one-sided printing	?	---	---
Outdoors	Adaptable size, full colour, one-sided printing	?	---	---
Website	Page in CML's website and standalone website	-	---	---
Tablets	Lent by IPL – 1 for 2 interviewers	16	---	---
Routers	Paid to operator or lent by IPL – 1 for 2 interviewers	16	---	---
Informed Consent	10 pages, A4, double sided printing, black & white colour, one for each participant	9 000	---	---
Project Management tool	Annual subscription – used to manage teams, scheduling and communication (i.e. Notion, Teams, etc.)	-	---	---

5.8.7. Personas

“In effect, personas are the users’ representatives or stand-ins during the design process.” (Engelhart & Moughamian, 1971). In Human Centred Design, people need to be understood (Calvo & Peters, 2014; Ku & Lupton, 2020), however it would be virtually impossible to design something that would work perfectly for everyone, so personas are used, which are an archetype of a select group of people (B. M. Ferreira et al., 2016; Martin & Hanington, 2012; Miaskiewicz &

Kozar, 2011) and can be used to generalize the wants and needs of their respective users.

In this project, the methodology of creating personas was employed to develop the ideal field team for the study. To this end, three main archetypes were projected (Figure 21), each with three subdivisions representing the possible ways of collaborating. Due to budget constraints, the stakeholders wanted to understand the implications of working with paid staff, volunteers or university students.

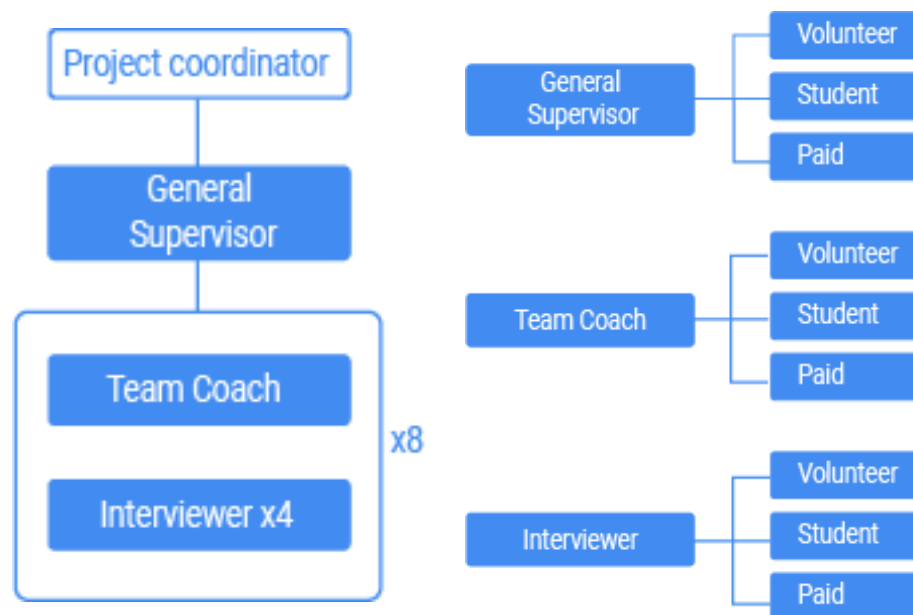


Figure 21. Field team personas. Three main archetypes and three motivation subdivisions. Made by author.

Therefore, in total, nine personas were created (Appendix C), three for each of the roles in the field team, general supervisor, team coach and interviewer. These would allow the stakeholders to define which type of person who would best suit the needs of the study. Creating

archetypes would make it easier and quicker to select people when the time came to start the study.

The information used to create these personas was taken from the interviews carried out with the population, where they were asked about the type of people they would (or would not) open their doors to. The finalisation of the development and validation of the personas was done in workshops with stakeholders developed by the other student of the design team. The workshop format would allow workshop participants to stick stickers on the areas with which they agreed or disagreed. The (Table 10) shows the list of characteristics presented in the workshop.

Table 10. Persona characteristics presented in workshop. Made by author.

Criteria	Supervisor	Team coach	Interviewer
Inclusion	Team manager Experience with paperwork Communication adaptability	Driver's Licence Good team manager Communication adaptability	Good in a team Communication adaptability
Exclusion	Low Literacy Low Digital Literacy Unfamiliarized with the Portuguese language (pt-pt) Use of terms not from pt-pt	Low Literacy Low Digital Literacy Visible tattoos Excessive facial piercings Unfamiliarized with the Portuguese language (pt-pt) Use of terms not from pt-pt	Low Literacy Low Digital Literacy Visible tattoos Excessive facial piercings Unfamiliarized with the Portuguese language (pt-pt) Use of terms not from pt-pt
Physical appearance	Well kempt appearance Clean person	Well kempt appearance Clean person	Well kempt appearance Clean person

	Good dental hygiene	Good dental hygiene	Good dental hygiene
	Clean skin	Clean skin	Clean skin
	Good posture and presentation	Good posture and presentation	Good posture and presentation
	Use of uniform	Use of uniform	Use of uniform
Personality	Proactive	Proactive	Proactive
	Autonomous	Autonomous	Kind
	Problem solver	Problem solver	Charismatic
	Responsible	Responsible	Good communicator
	Kind	Kind	Mediator
	Charismatic	Charismatic	Empathetic
	Good communicator	Good communicator	Punctual
	Mediator	Mediator	Diligent
	Empathetic	Empathetic	
	Punctual	Punctual	
	Diligent	Diligent	
	Organized	Organized	
Technical Skills	Team management experience	Experience in customer service	Experience in customer service
	Experience with date management software	Sales experience	Sales experience
	Experience as Project Manager	High literacy	High literacy
	Experience in Backoffice	High digital literacy	High digital literacy
	Experience with filling out reports	Team management experience	
	Planning capabilities	Familiarity with management software	
	Familiarity with data analysis	Experience with filling out reports	
	Experience in customer service		

These base personas were then divided into their subtypes (volunteer, student or paid), each with different motivations, objectives and responsibilities (Table 11, 12). At first glance, these characteristics may seem repetitive, but they have been intentionally

designed as such, with the intention of showing stakeholders how much the responsibilities required for each role can be impacted by the motivations of the three types of profiles, for example, a student whose motivation is to earn some extra credits, but who does not yet have work experience, would not be the best choice for the position of supervisor.

Table 11. Persona motivations divided by role. Made by author.

Supervisor	Habits	Motivations	Objectives
Volunteer	Likes to volunteer Likes to do things on their free time Enjoys socializing	Wants to be part of something new Wants to be part of the study to help their community	Be a part of something new in their community
Student	Studying Hanging out with friends Extracurricular activities	Has something they can gain from the experience The experience may count as an internship	Extra credit Professional Experience while still in school
Paid/ Employed	Is looking for a job Works overtime	Opportunity to earn money Opportunity for more work experience	Earn money Gain more communication experience Gain more work experience
Team Coach	Habits	Motivations	Objectives

Volunteer	Likes to volunteer Likes to do things on their free time Enjoys socializing	Wants to be part of something new Wants to be part of the study to help their community	Be a part of something new in their community
Student	Studying Hanging out with friends Extracurricular activities	Has something they can gain from the experience The experience may count as an internship	Extra credit Professional Experience while still in school
Paid/ Employed	Is looking for a job Works overtime	Opportunity to earn money Opportunity for more work experience	Earn money Gain more communication experience Gain more work experience
Interviewer	Habits	Motivations	Objectives
Volunteer	Likes to volunteer Likes to do things on their free time Enjoys socializing	Wants to be part of something new Wants to be part of the study to help their community	Be a part of something new in their community
Student	Studying Hanging out with friends Extracurricular activities	Has something they can gain from the experience	Extra credit Professional Experience while still in school

		The experience may count as an internship	
Paid/ Employed	Is looking for a job Works overtime	Opportunity to earn money Opportunity for more work experience	Earn money Gain more communication experience Gain more work experience

Table 12. *Persona's objectives and responsibilities. Made by author.*

Roles	Objectives	Responsibilities
Supervisor	Keeping the teams optimized Ensuring the study's continuation	Distribute and manage the teams Plan the calendar Perform weekly statistics Be available and open to answer any possible question for information (from the teams or the population) Manage conflicts
Team Coach	Ensuring the interviewers interactions are performed according to the script and handbook	Aiding in taking their team to their respective locations Managing their team on the field Manage any possible conflicts
Interviewers	Keeping the population focused and motivated	Point of contact with the population Presenting the study Performing the questionnaire

The final result of using personas methodology was achieved after all nine personas developed had been tested at the "Green and Red Feedback Workshop" conceived by my colleague Daniela Marques and held by the design team. In this workshop, the final personas to be used in each function were chosen, refined and finalised with input from the stakeholders (Table 13).

Table 13. Finalized personas. Made by author.

Criteria	Supervisor	Team coach	Interviewer
Exclusion	Low Literacy Low Digital Literacy Unfamiliarized with the Portuguese language (pt-pt) Use of terms not from pt-pt	Low Literacy Low Digital Literacy Visible tattoos Excessive facial piercings Unfamiliarized with the Portuguese language (pt-pt) Use of terms not from pt-pt	Low Literacy Low Digital Literacy Visible tattoos Excessive facial piercings Unfamiliarized with the Portuguese language (pt- pt) Use of terms not from pt-pt
Physical appearance	Well kempt appearance Clean person Good dental hygiene Clean skin Good posture and presentation Use of uniform	Well kempt appearance Clean person Good dental hygiene Clean skin Good posture and presentation Use of uniform	Well kempt appearance Clean person Good dental hygiene Clean skin Good posture and presentation Use of uniform
Personality	Proactive Autonomous Problem solver	Proactive Autonomous Problem solver	Proactive Kind Charismatic

	Responsible	Responsible	Good
	Kind	Kind	communicator
	Charismatic	Charismatic	Mediator
	Good	Good	Empathetic
	communicator	communicator	Punctual
	Mediator	Mediator	Diligent
	Empathetic	Empathetic	
	Punctual	Punctual	
	Diligent	Diligent	
	Organized	Organized	
Technical Skills	Team management experience	Experience in customer service	Experience in customer service
	Experience with data management software	Sales experience	Sales experience
	Experience as Project Manager	High literacy	High literacy
	Experience in Backoffice	High digital literacy	High digital literacy
	Experience with filling out reports	Team management experience	
	Planning capabilities	Familiarity with management software	
	Familiarity with data analysis	Experience with filling out reports	
	Experience in customer service		

5.8.8. Web Design

The aim of the LISA study website was to inform the population about the characteristics of the study. As it was intended for the general population, it was important to present a simple and clear navigability, graphic layout, language and interaction. Because some of its users would have lower levels of education and digital literacy, it was important to have an inclusive design approach.

For the study, an independent website and a section to be included on the CML website were designed.

5.8.8.1. Independent website

For the development of the independent website, I began by idealising a single-page website where the user would only have to scroll to access the information (Figure 22). The development stages of the website began by collecting, organising and adapting the information about the study. The processing of the information then resulted in the structuring of the sections that would compose the website. The descriptive text was developed using accessible language and vocabulary to ensure easy understanding by people with different levels of education. For the same reasons, the text was also very concise and clear.

Home

Who we are/ Our objective

Presenting

Importance

Study's Design

Who can be
a part of the
study

Organization

Responsible
entities

Calendar

Calendar

Galery

Images of Leiria and
the responsible
entities

FAQ's

FAQ's

Contacts

Important
contacts

Figure 22. First website structure. Made by author.

Next, the graphic contents were developed based on the study's brand created earlier.

A first version of the website was then organised on one page (Figure 23).



Cont...



Figure 23. Website first Version. Made by author.

When this version of the website was presented to the stakeholders, they expressed their preference for a separate page structure to avoid people getting lost in the scroll. As a result, a second version of the website was created (Figure 24), consisting of a menu at the top that gave access to the different sections, now separated into different pages.

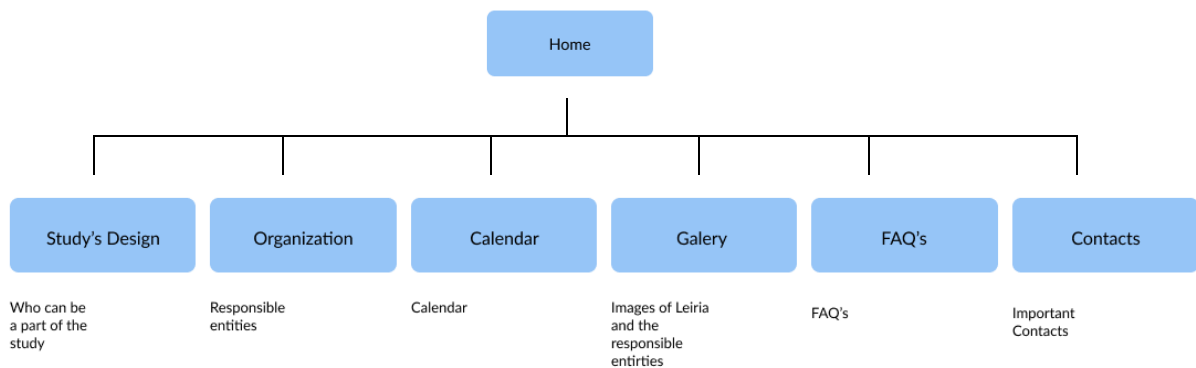


Figure 24. Structure of the second version of the website. Made by author.

This second version (Figure 25-31) was approved by the stakeholders. Throughout the process of developing the interactive prototype of this version there were minor changes before it was presented to the stakeholders to receive their feedback.


For web viewers
Prototype Here -> 
lisa



Figure 25. Second version: Homepage. Made by author.

lisa home o estudo participantes calendário galeria FAQ's contactos

Importância do estudo

Nos últimos anos, vários estudos têm demonstrado que um nível inadequado de literacia em saúde pode ter implicações na saúde dos cidadãos, na utilização dos serviços de saúde e, conseqüentemente, nos gastos em saúde.

Portugal é o país onde foi registado a maior percentagem de nível "suficiente" de literacia em saúde: 65%. E onde 7,5% das pessoas foram classificadas com um nível "inadequado" e 22% pessoas foram classificadas com um nível "problemático".

Nível	Porcentagem
Problemático	22%
Inadequado	7,5%
Suficiente	65%
Desconhecido	5,5%

Por estas razões, é urgente realizar um estudo para caracterizar a literacia em saúde do concelho de Leiria, de forma a adequar as melhores práticas e organização de cuidados e políticas em saúde.

Tipologia de estudo

É um estudo colaborativo multidisciplinar que junta diferentes entidades do concelho de Leiria. O estudo Lisa é promovido por:

- POLITÉCNICO DE LEIRIA** | ciTechCare CENTER FOR INNOVATIVE CARE IN HEALTH TECHNOLOGY
- ciTechCare – Centro de Inovação em Tecnologias e Cuidados de Saúde do Politécnico de Leiria
- Município de Leiria
Câmara Municipal de Leiria
- ACES PINHAL LITORAL
ACES Pinhal Litoral
- LIDA**
Lida – Laboratório de Investigação em Design e Artes.

Figure 26. Second version:
Study description page.
Made by author.



Figure 27. Second version: Participants Page. Made by author.

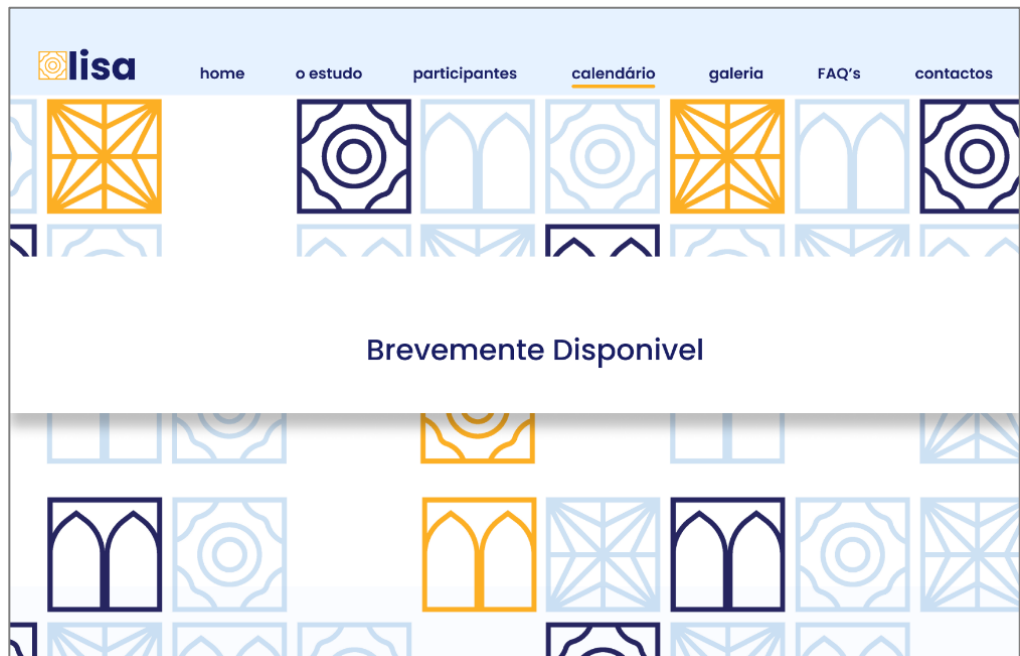


Figure 28. Second version: Calendar Page. Made by author.

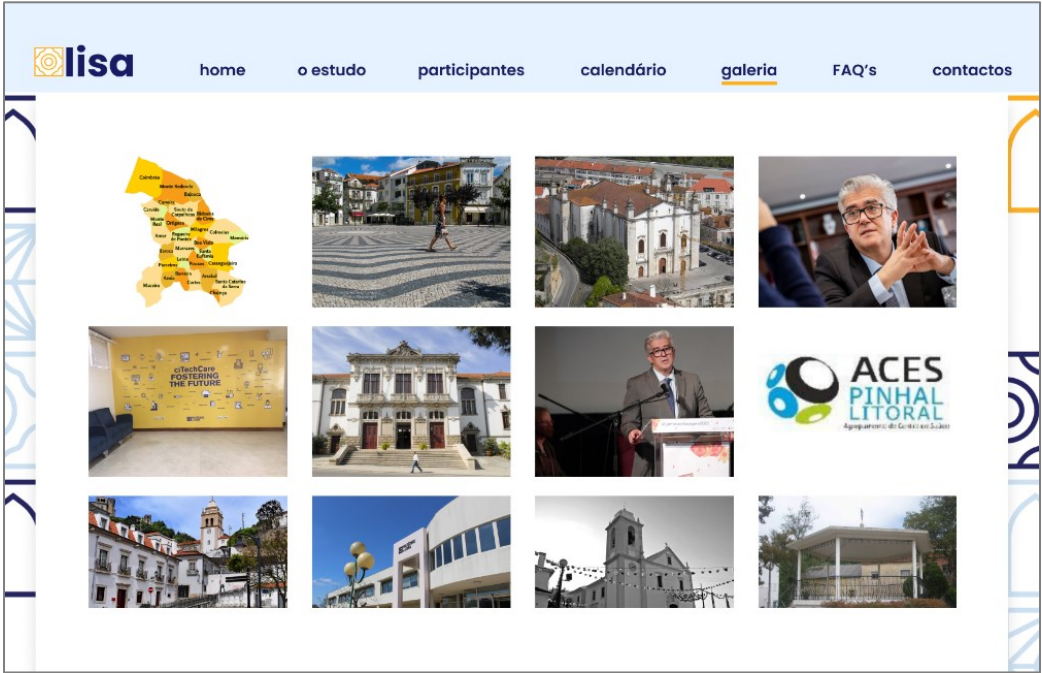


Figure 29. Second version: Gallery Page. Made by author.

lisa home o estudo participantes calendário galeria **FAQ's** contactos

Perguntas frequentes

O que é o estudo Lisa?
É um estudo cujo objetivo é medir a literacia em saúde na população adulta residente no concelho de Leiria ao longo dos próximos 10 anos. Este estudo é promovido pelo ciTechCare – Centro de Inovação em Tecnologias e Cuidados de Saúde do Politécnico de Leiria em parceria com a Câmara Municipal de Leiria, a ACES Pinhal Litoral e o Lida – Laboratório de Investigação em Design e Artes.

O que é literacia em saúde?
A OMS – A organização Mundial de Saúde (DGS, 2019) define Literacia em Saúde como “o grau em que os indivíduos têm a capacidade de obter, processar e entender as informações básicas de saúde para utilizarem os serviços e tomarem decisões adequadas de saúde”, sabendo-se que esta contribui não só para promoção da saúde e prevenção da doença, mas também para contribuir para a eficácia e eficiência dos serviços de saúde.

Porque é importante realizar um estudo em Literacia em Saúde?
Portugal é o país onde foi registado a maior percentagem de nível “suficiente” de literacia em saúde: 65%. E onde 7,5% das pessoas foram classificadas com um nível “inadequado” e 22% pessoas foram classificadas com um nível “problemático”. Por estas razões, é urgente realizar um estudo para caracterizar a literacia em saúde do concelho de Leiria, de forma a adequar as melhores práticas e organização de cuidados e políticas em saúde.

O que é que eu ganho em participar no estudo Lisa?
Não há benefícios diretos, contudo, ao participar no estudo terá informação XX

Quais são os riscos associados à minha participação no estudo Lisa?
Não há riscos em participar no estudo Lisa. (adicionar texto sobre a identidade e os dados do participante estarem protegidos)

Quem autorizou a realização do estudo Lisa?
O estudo Lisa foi construído de modo a cumprir as boas práticas clínicas e o Regulamento Geral de Proteção de Dados (RGPS). Adicionalmente, este estudo foi aprovado pela Comissão de Ética(1) do Politécnico de Leiria.

(1) <https://www.ipleiria.pt/investigar/investigar/comissao-de-etica/>

Figure 30. Second version: FAQs Page. Made by author.

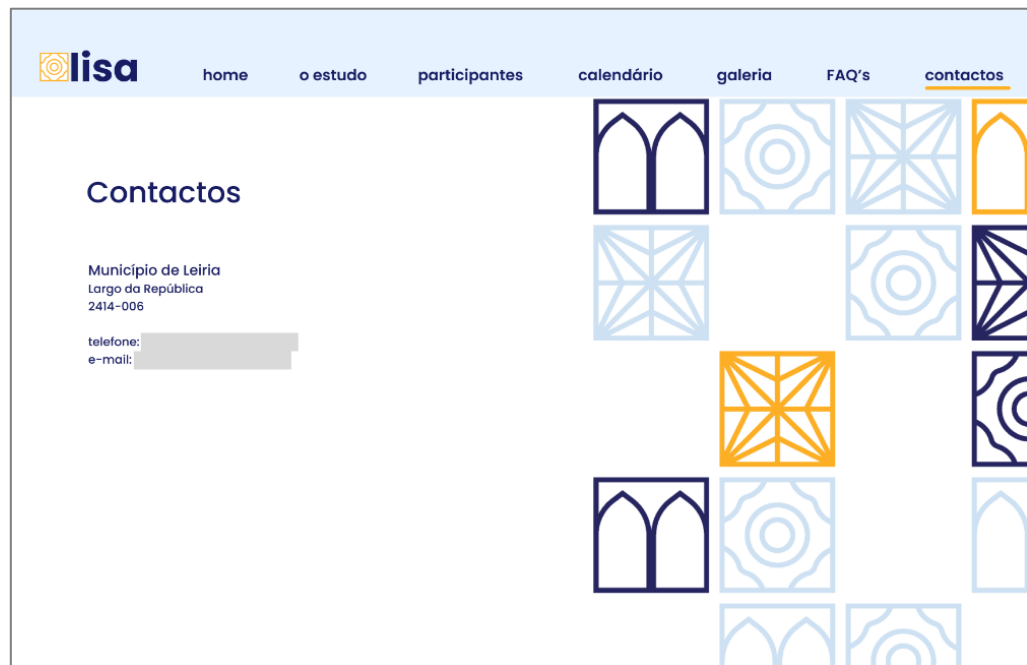


Figure 31. Second version: Contacts Page. Made by author.

5.8.8.2. Page for the CML website

Next, a page (Figure 32) was developed to be included on the CML - Câmara Municipal de Leiria - website.

The information and graphic content developed before for the independent website has been adapted so that it is all concentrated on one page/section and fits in with the layout of the CML website. Compared to the independent website, the content of the image gallery was excluded because it was not relevant here, giving priority to a quicker reading of the study description.



Município de
Leiria

o que procura?

MUNICÍPIO
ÁREAS DE ATIVIDADE
VISITE LEIRIA
ÁREA DO MUNICÍPIO
Estudo Lisa



Estudo Longitudinal de Literacia em Saúde no Concelho de Leiria

Saber Ser Saúde

O Estudo Lisa (1)
Tem como principal objetivo medir a literacia em saúde(2) na população adulta residente no concelho de Leiria ao longo dos próximos 10 anos. É um estudo essencial, de base populacional que permitirá a análise dos dados em saúde numa amostra representativa da população do concelho de Leiria. Este estudo servirá para auxiliar na planificação de estratégias de organização de cuidados e políticas em saúde.

A participação de todos é muito importante, pois só assim conseguiremos caracterizar a literacia em saúde do concelho de leiria, perceber as lacunas e melhorar os cuidados de saúde prestados a estas pessoas.

(1) Este é um estudo de coorte que se desgrna por estudar e acompanhar uma amostra da população por um determinado intervalo de tempo.
(2) A literacia em saúde consiste no grau de conhecimento que se tem em saúde.

Importância do estudo

Nos últimos anos, vários estudos têm demonstrado que um nível inadequado de literacia em saúde pode ter implicações na saúde dos cidadãos, na utilização dos serviços de saúde e, consequentemente, nos gastos em saúde.

Portugal é o país onde foi registado a maior percentagem de nível "suficiente" de literacia em saúde: 65%. E onde 7,6% das pessoas foram classificadas com um nível "inadequado" e 22% pessoas foram classificadas com um nível "problemática".



Problemática	22%
Inadequado	7,6%
Suficiente	65%
Desconhecido	5,5%







Por estas razões, é urgente realizar um estudo para caracterizar a literacia em saúde do concelho de Leiria, de forma a adequar as melhores práticas e organização de cuidados e políticas em saúde.

Tipologia de estudo
É um estudo colaborativo multidisciplinar que junta diferentes entidades do concelho de Leiria. O estudo Lisa é promovido por:

 **POLITÉCNICO DE LEIRIA** UNIVERSIDADE POLITÉCNICA DE LEIRIA

cITechCare – Centro de Inovação em Tecnologias e Cuidados de Saúde do Politécnico de Leiria

 **Município de Leiria**
Câmara Municipal de Leiria

 **ACES PINHAL INTERIOR**
ACES Pinhal Interior

LIDA
Lida – Laboratório de Investigação em Design e Artes.

Quem vai participar

Toda a população com mais de 17 anos residente no concelho de Leiria poderá participar no estudo. Os dados vão ser recolhidos pessoalmente através de entrevistas pessoais assistidas por computador. A amostra* será representativa por escolaridade etária e sexo.

* Os participantes

		Participantes	
		Mulheres	Homens
Idade – Anos	18-29	565	565
	30-34	570	570
	35+	567	565
	Total	2002	2000

Perguntas frequentes

O que é o estudo Lisa?
É um estudo cujo objetivo é medir a literacia em saúde na população adulta residente no concelho de Leiria ao longo dos próximos 10 anos. Este estudo é promovido pelo cITechCare – Centro de Inovação em Tecnologias e Cuidados de Saúde do Politécnico de Leiria em parceria com a Câmara Municipal de Leiria, o ACES Pinhal Interior e o Lida – Laboratório de Investigação em Design e Artes.



O que é literacia em saúde?
A OMS – A Organização Mundial de Saúde (OMS, 2019) define literacia em Saúde como “o grau em que os indivíduos têm a capacidade de obter, processar e entender as informações básicas de saúde para utilizarem os serviços e tomarem decisões adequadas de saúde”, sabendo-se que esta contribui não só para promoção da saúde e prevenção de doença, mas também para contribuir para a eficácia e eficiência dos serviços de saúde.

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Quais são os riscos associados à minha participação no estudo Lisa?
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Quem autorizou a realização do estudo Lisa?
O estudo Lisa foi construído de modo a cumprir as boas práticas clínicas e o Regulamento Geral de Proteção de Dados (RGPD). Adicionalmente, este estudo foi aprovado pela Comissão de Ética(1) do Politécnico de Leiria.

(1) <https://www.pluris.pt/investigacao/investigacao/comiteas-de-eticas/>

Município de Leiria
Ligação ao Município
344 600 1000

Colégio das Artes
CML - Centro Municipal de Leiria

Participem nos estudos
Navegar
Socializar
Papel PDF

1000 000



Figure 32. Page for the CML website. Made by author.

For web viewers

Prototype Here ->



5.8.9. Guidelines for the development of cohort studies

From all the interviews, experiences gained in the development of the project and the participation of the design team, a list of guidelines was compiled (Table 14) to help in the development of future projects of a similar nature and in the integration of new members into the multidisciplinary team. These were also included in a document to be used as future reference (Appendix B).

Although these guidelines may need to be adjusted according to the subject matter of other studies, this list focuses some of the most important topics and steps to consider in the preparation phase of a study of this type.

Table 14. Guidelines. Netto-Rocha, C. Marques, S. 2022.

Type	Guidelines
Study	<ul style="list-style-type: none"> ▪ Carry out advisory interviews with experts from similar studies ▪ Define the audience of the study (i.e. quantity, sample) ▪ Define and keep the study timetable up to date ▪ Define the study methodology (i.e. door-to-door, telephone...) ▪ Test the study's media (in this case the questionnaire) with the population ▪ Define the communication strategy ▪ Ensure that the public is familiarised with the study before fieldwork begins (i.e. advertisements, posters, billboards, flyers, outdoors) ▪ Define the organization of the field team (hierarchy) ▪ Develop and train the field team
Team	<ul style="list-style-type: none"> ▪ Have an internal communication channel between the members of the multidisciplinary team

- Schedule meetings with the multidisciplinary team at least once a month (this helps to follow the timeline without deviations, and to keep everyone up to date with what has been developed)
- Structure the work to be developed in the field (i.e. workshops with the multidisciplinary team)
- Define the communication strategy
- Define the organization of the field team (hierarchy)
- Develop and train the field team
- Ensure the correct identification of the field team during their shifts

-
- Designers**
- Adapt communication for the design team (to avoid misunderstandings)
 - Seek advice by conducting interviews with experts from similar studies
 - Conduct interviews with the study's target population
 - Select the design methodologies to be applied
 - Create a recognizable brand with the study team (i.e. name, symbols, logo, signature)
 - Create physical and digital media content that will be used to communicate the study
 - Organise the fieldwork workshops
 - Define the sample of population to be interviewed using the *User Groups Definition* method
 - Define the communication strategy
 - Define the ideal profiles of the people who will be in contact with the population using the *Personas* methodology
 - Develop support materials for organising the study (logbook, budgets, operational plan)
 - Create a manual or guide to assist in contacting with the population (interviewer's manual and logbook)
-

5.8.10. Interviewer's Handbook

The ultimate result of all the experience gathered in the process of developing the study and this project was the creation of the

Interviewer's Handbook (Appendix A) to be used during the training of interviewers and for use in the field. This manual was developed in collaboration with the stakeholders and the multidisciplinary team. The Interviewer's Handbook (Figure 33) is a compilation of scripts, guidelines and tips, protocols for introducing the study to the population, i.e. how interviewers should present themselves. This manual also contains the full questionnaire with tips on how to help interviewees without inserting bias into the study.

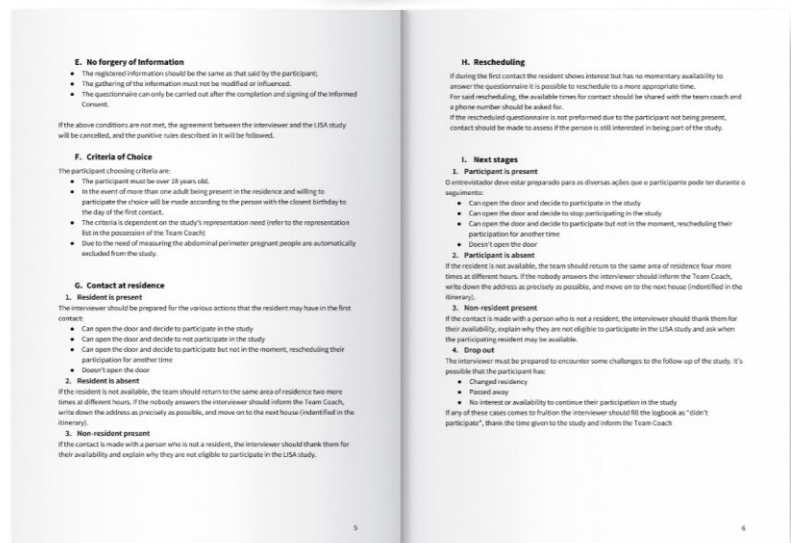


Figure 33. Interviewer's handbook.
Made by author.

Chapter 6. Final Considerations

Having completed all the work, it is now possible to start answering the research questions posed at the beginning of this process. Yes, a designer can indeed be part of a cohort study, even playing a decisive role in decision-making and study planning. It can also be said that they can be part of multidisciplinary teams, adapting their language and communication, and even making use of design methods to facilitate the flow of communication and compile information in a format that is easy for everyone to understand and thus establish common ground between all team members.

We realised the importance of good communication with stakeholders in clarifying what the field of design can contribute to the development and implementation of a cohort study. Initially, the stakeholders thought that the designers would only develop the study's logo and some communication formats. This is achieved by organising meetings with all members present, opening up an open channel of communication, eliminating possible prejudices or doubts and allowing a clear understanding of each person's role. This is also achieved by the results presented resulting from the use of the design methods utilised by the designers in the development of the study.

The use of design methods in the early stages of this type of study makes it possible to speed up its development by accelerating the information-gathering phase. By successfully using these methods, it is possible to understand the needs of the stakeholders, the

multidisciplinary team, the operational team and the population, and to adapt the entire study to those needs.

The process of selecting and training the interviewers for this study was created through the use of various design methods. Applying the method of creating Personas allowed the designer to create personality archetypes for each role and the motivation a person might have for being part of the study's operational team. This allowed for a better understanding of the needs that the stakeholders had to keep in mind when selecting the members of the study's operational team. In addition, by developing an interviewer's manual, the designers ensured that all the people selected had the same guidelines for carrying out their roles and the correct guidelines to ensure quality information collection.

Having answered these questions, there were other challenges faced by the multidisciplinary team caused by several factors.

The challenge caused by the change of people in CML team following the regional elections. This change resulted in a delay in the study's timetable and a new process of clarifying the importance of the design domain's contribution to the development of the LISA study.

Another factor that made it difficult to meet the study's schedule was that the preparatory phase began in 2021, at the height of the Covid-19 pandemic. This fact made it difficult to gather people to be part of the sample of the population interviewed, probably if we weren't in a pandemic situation, it would have made it easier to get a larger sample. The pandemic also made it difficult to schedule meetings with the multidisciplinary team, given that most of the members were

practising public health doctors with increased responsibilities in their field.

It should also be noted that due to time constraints (finalising the collaboration with the master's program) the designers were only present during the preparatory phases of the study. This did not allow them, for example, to monitor the production of communication materials (i.e. social media posts, flyers, posters, etc.), resulting in some changes to the brand's visual elements, such as the brand's main colours.

To avoid some of these challenges in future cohort studies, it is advisable:

- That the multidisciplinary team undergoes as few changes of members as possible;
- Designers should be present since the start of the study and their presence should be maintained throughout all phases of the study until its conclusion;
- Definition of strategies to facilitate communication and collaboration between the study and the population.

In conclusion, the designers developed fundamental materials for the operationalisation of this study and these can be adapted to other studies of a similar nature. The guidelines developed can also help future teams. In addition, it is important to emphasise the various participations in conferences and publications of articles made by the designers, which confirm the importance that this work has represented for knowledge in the field of design.

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Appendixes

A. Interviewer's Handbook

This Interviewer's Handbook has been compiled for the use in the LISA study. The questionnaire with the interviewer behaviour hints, has been separated from this section and will be presented in it's own section



Interviewer's Handbook

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I. Introduction to LISA

LISA is a longitudinal study whose main objective is to measure health literacy in the adult population living in the county of Leiria over the next few years. It is a population-based study that will allow the analysis of health outcomes in a representative sample of the adult population of this county. The study will also serve to help in the planning of strategies for the organisation of health policies.

For the characterization of health literacy, comprehension of the gaps, and improvement of healthcare services in the county of Leiria, it is essential that the population of Leiria actively participates in LISA.

II. Interviewer Responsibilities

A. Identification

The LISA study ID card and t-shirt should be collected from the supervisor 15 minutes before leaving for the interviews with the population. Their use is mandatory during all moments of contact with the population, and they should only be removed when delivered to the supervisor at the end of the interviewers' shift.

The gathering of ID cards and t-shirts will help monitor the participation of the interviewer. These elements can never be used for any purpose other than the study and may justify the cancellation of the agreement between the interviewer and the LISA study.

B. Proof of Address

At the first contact the interviewer must ask for proof of address (i.e. mail letter). Only after the proof is provided should the contact be resumed.

In the event no proof of address is provided the person should be excluded from the study. The document provided as proof should only be used to validate the resident as a participant.

C. Providing Information

During the contact with the population, the interviewer has the duty to present the objectives of the LISA study to the participants, and clarify any existing doubts.

At this point, the Informed Consent document should also be given to the resident who has agreed to participate, asking him/her to sign two equal documents. One of the documents should be given to the participant, and the other should be saved and delivered to the Team Coach after the interview.

The interviewer should give the participant the Leaflet with an explanation of the study and contacts. At the end of the interview, the participant should be given the loyalty card signed by the Team Coach.

D. Confidentiality of Information

- Demographic Data
- Contacts
- Questionnaire specific data
- Informed Consent

Any and all information collected during the stay at the participant's house must be confidential*. The above-mentioned elements must not be copied, shared or used for any purpose other than the LISA study.

In the event the former condition is not verified the agreement made between the interviewer and the LISA study will be canceled.

*The only exception being a public crime (i.e. domestic violence).

E. No forgery of Information

- The registered information should be the same as that said by the participant;
- The gathering of the information must not be modified or influenced.
- The questionnaire can only be carried out after the completion and signing of the Informed Consent.

If the above conditions are not met, the agreement between the interviewer and the LISA study will be cancelled, and the punitive rules described in it will be followed.

F. Criteria of Choice

The participant choosing criteria are:

- The participant must be over 18 years old.
- In the event of more than one adult being present in the residence and willing to participate the choice will be made according to the person with the closest birthday to the day of the first contact.
- The criteria is dependent on the study's representation need (refer to the representation list in the possession of the Team Coach)
- Due to the need of measuring the abdominal perimeter pregnant people are automatically excluded from the study.

G. Contact at residence

1. Resident is present

The interviewer should be prepared for the various actions that the resident may have in the first contact:

- Can open the door and decide to participate in the study
- Can open the door and decide to not participate in the study
- Can open the door and decide to participate but not in the moment, rescheduling their participation for another time
- Doesn't open the door

2. Resident is absent

If the resident is not available, the team should return to the same area of residence two more times at different hours. If the nobody answers the interviewer should inform the Team Coach, write down the address as precisely as possible, and move on to the next house (identified in the itinerary).

3. Non-resident present

If the contact is made with a person who is not a resident, the interviewer should thank them for their availability and explain why they are not eligible to participate in the LISA study.

H. Rescheduling

If during the first contact the resident shows interest but has no momentary availability to answer the questionnaire it is possible to reschedule to a more appropriate time.

For said rescheduling, the available times for contact should be shared with the team coach and a phone number should be asked for.

If the rescheduled questionnaire is not performed due to the participant not being present, contact should be made to assess if the person is still interested in being part of the study.

I. Next stages

1. Participant is present

O entrevistador deve estar preparado para as diversas ações que o participante pode ter durante o seguimento:

- Can open the door and decide to participate in the study
- Can open the door and decide to stop participating in the study
- Can open the door and decide to participate but not in the moment, rescheduling their participation for another time
- Doesn't open the door

2. Participant is absent

If the resident is not available, the team should return to the same area of residence four more times at different hours. If the nobody answers the interviewer should inform the Team Coach, write down the address as precisely as possible, and move on to the next house (identified in the itinerary).

3. Non-resident present

If the contact is made with a person who is not a resident, the interviewer should thank them for their availability, explain why they are not eligible to participate in the LISA study and ask when the participating resident may be available.

4. Drop out

The interviewer must be prepared to encounter some challenges to the follow-up of the study. It's possible that the participant has:

- Changed residency
- Passed away
- No interest or availability to continue their participation in the study

If any of these cases comes to fruition the interviewer should fill the logbook as "didn't participate", thank the time given to the study and inform the Team Coach

III. Guide/protocol of interviewer actions during the questionnaire

A. Questionnaire Description

We are part of the LISA study team - Longitudinal Study of Health Literacy in the Municipality of Leiria and, first of all, we would like to explain the objectives of this survey. It is framed in the Municipal Health Strategy of the Municipality of Leiria. The project is aligned with the main documents in the health area, with its objectives and actions focused on health promotion. For this, we intend to monitor people living in the municipality of Leiria, over several years, in order to assess the level of health literacy and some health determinants (diabetes, mental health, smoking and alcohol).

Thus, we ask you to answer a set of questions regarding your health and indicate the degree of difficulty you feel in performing tasks relevant to that management.

Your answers are completely confidential.

B. Questions about the study's dissemination

After introducing the study the interviewer should ask the participant:

Have you heard about LISA? (por publicidade ou cartaz)

If yes from where?

C. Information Registration

The interviewer should register all the information provided by the resident on the tablet and in the logbook. If this is not possible (due to lack of internet or battery) the contact will be rescheduled.

At the end of an interview, if the battery of the tablet is running out and the powerbank is not supporting the device, the interviewer should not go to the next house until the battery is re-established (100%)

All data registered on the tablet and in the logbook will be confirmed later by the supervisor and project coordinator. Every ___ in ___ answers, these entities should contact the participant and ask for feedback about the application of the questionnaire, confirming that the data collected is accurate. The collected data should be analyzed monthly to monitor their quality. This statistical analysis will be performed on different levels:

The data gathered should be monitored daily and if any problems are identified, the supervisor should intervene.

The data should be analysed monthly in order to monitor their quality. This statistical analysis will be carried out at different levels: by teams of interviewers, by parishes, age groups and gender; with the aim of minimising data errors.

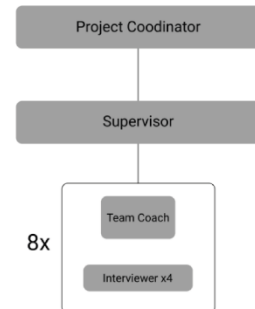
The data will be stored in a specific server with a high level of security.

IV. Organization

A. Work System

The hierarchy present in the LISA study consists of four levels, the highest being the Project Coordinator, followed by the Supervisor, who has below him the Team Coaches responsible for their teams of Interviewers.

- **Project Coordinator** - Responsible for the LISA study and the data analysis resulting from the questionnaires.
- **Supervisor** - Responsible for managing the teams and answering questions from the population
- **Team Coach** - Responsible for maintaining the organization of his team in the field.
- **Interviewer** - Responsible for contacting the population and collecting data for the study.



Since the territory of the municipality of Leiria is vast, and according to the time allotted for the implementation of the questionnaires, it is recommended to have eight teams. It is recommended that each field team be composed of five members, four Interviewers and a Team Coach. During the interviews, the Interviewers should be divided into pairs, and it is recommended that each pair be made up of one female and one male.

B. Materials to bring to the field

- ID Cards
- Documents (Informed Consent, Flyer, Logbook)
- Itinerary
- Interviewer's Handbook
- Router/Hotspot
- Tablet with access to the questionnaire
- Umbrellas and waterproof trenchcoat
- Bottles of water
- Car - team's transportation throughout the itinerary
- Powerbank/ tablet charger
- Measuring tape

V. Other Role's Duties

A. Team coach

- Keep the itinerary given by the supervisor
- Take the team to the itinerary location
- Manage team in the field
- If in doubt contact Supervisor
- May perform interviews as a last resort (in case an interviewer feels unwell)
- Do daily reports

B. Supervisor

- Attend Interviewer training
- Manage the teams
- Define the script based on the representation tables updated by the coordinator
- Answer phone calls and respond to emails with questions from the population
- Organize project documentation
- In case of doubts, contact the project coordinator
- Keep the table of visited houses (logbook) up to date
- Perform weekly statistics of data collection in order to identify failures or incorrect data
- Call registered participants to confirm participation*
- Call to dropouts to confirm their choice

*To avoid falsification of information by interviewers.

C. Project Coordinator

- Validate the questionnaire responses,
- Organize the data received
- Update the population representation tables

VI. FAQs

(to be expanded upon the first interviewer training session, according to the resulting questions)

VII. Attachment

A. Logbook

The logbook will be a data entry table, printed or digital. All interviewers should have a copy with them. This table should be signed by the Team Coach after each interview and handed to the supervisor at the end of the shift. Below is an example of it.

Logbook - #__

No.	Citizen ID	Address			Date	Hour	Results				Interviewer (Name)	Team Coach (Signature)	Confirmation of Data (Supervisor)
		Street	no.	Parish			Post Code	Absent	Participated	Didn't Participate			
1							<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
2							<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3							<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
4							<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
5							<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
6							<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
7							<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
8							<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
9							<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
10							<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			

No.	Notes
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	

A.1 Logbook

Logbook - # ___

No.	Citizen ID	Address				Date	Hour	Results				Interviewer (Name)	Team Coach (Signature)	Confirmation of Data (Supervisor)
		Street	no.	Parish	Post Code			Absent	Participated	Didn't Participate	Rescheduled			
1								<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
2								<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
3								<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
4								<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
5								<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
6								<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
7								<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
8								<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
9								<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			
10								<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>			

No.	Notes
1	
2	
3	
4	
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10	

B. Guidelines

Guidelines for the preparation of a cohort study

Constança Rocha & Daniela Marques

2022/2023

For the study

- Counselling interviews with experts of similar studies
- Define the audience of the study (quantity, sample)
- Define and keep up-to-date with the study timeline
- Define the methodology of the study to be carried out (door-to-door/ calls)
- Test the study media (in this case questionnaire) with the population
- Define the communication strategy
- Ensure public familiarity with the study before the beginning of the fieldwork (advertising the study, posters, billboards, flyers, advertisings)
- Define the organisation of the field team (hierarchy)
- Develop and provide training for the field team

For the team

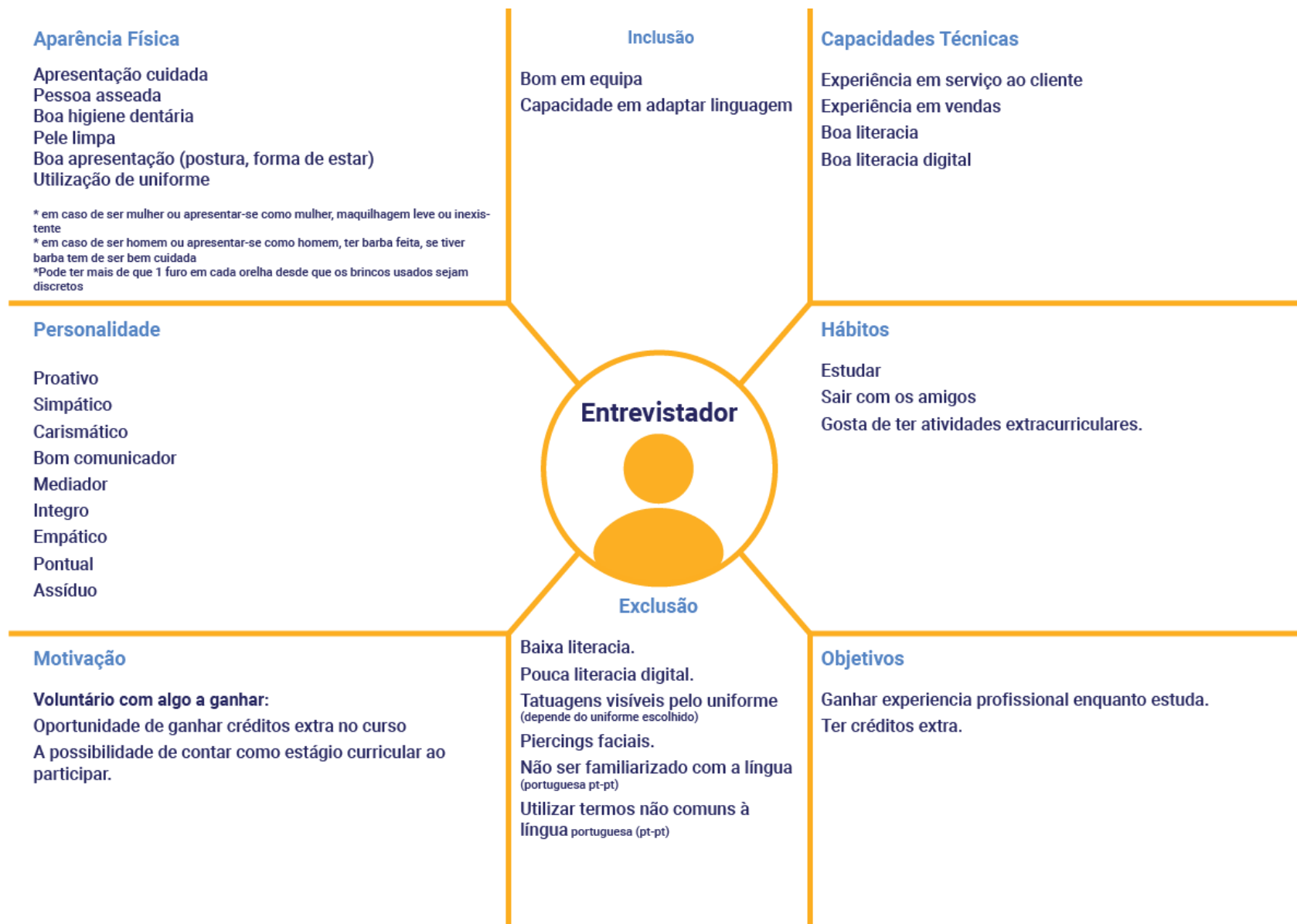
- Have a channel for internal communications between the members of the multidisciplinary team
- Schedule meetings with the multidisciplinary team at least once a month (this helps to follow the schedule without deviations, and to keep everyone informed of what has been developed)
- Structure the work to be developed in the field (workshops).
- Define the communication strategy
- Define the organisation of the field team (hierarchy)
- Develop and provide training for the field team
- Ensure that the field team is correctly identified during their shifts

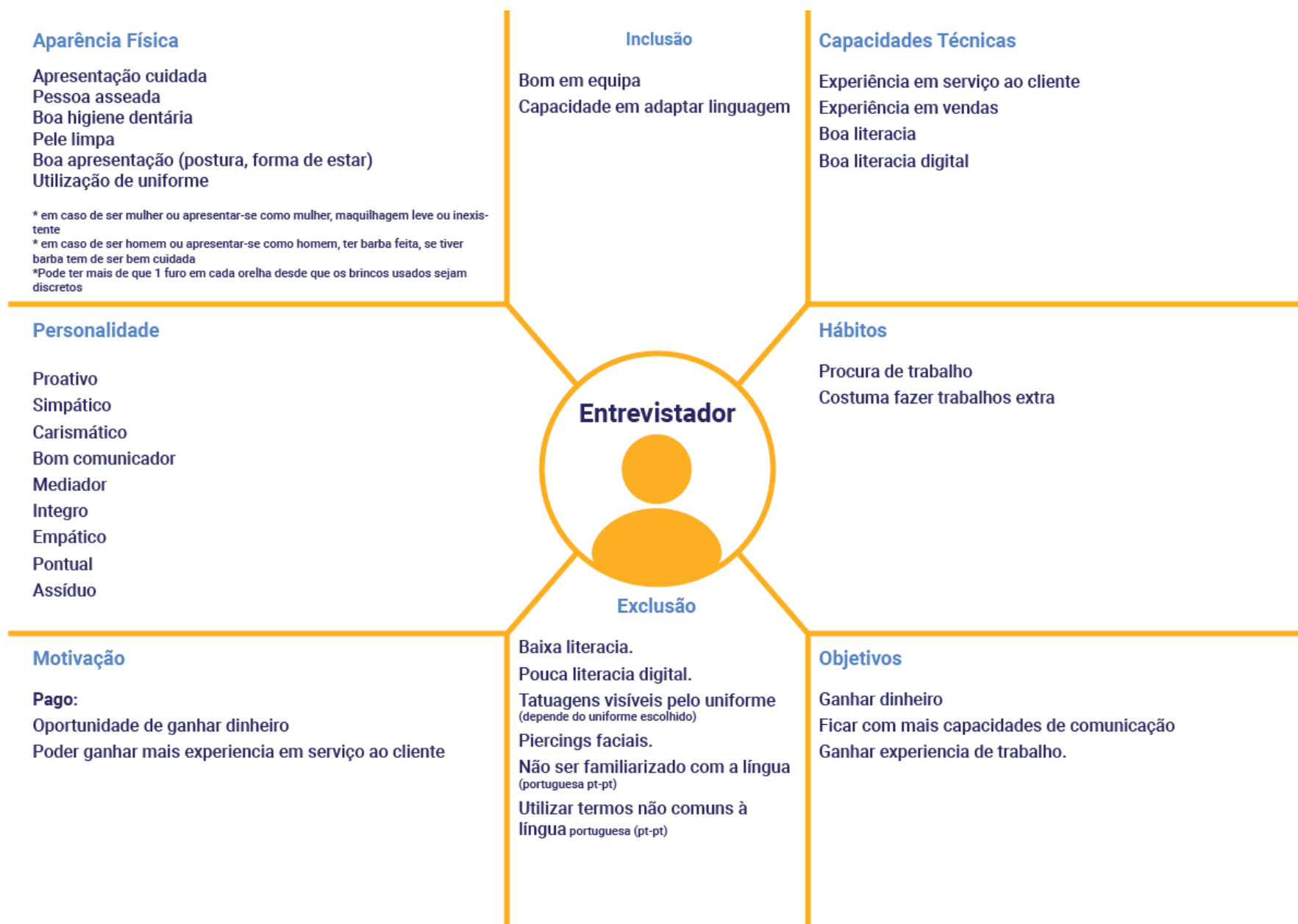
For designers

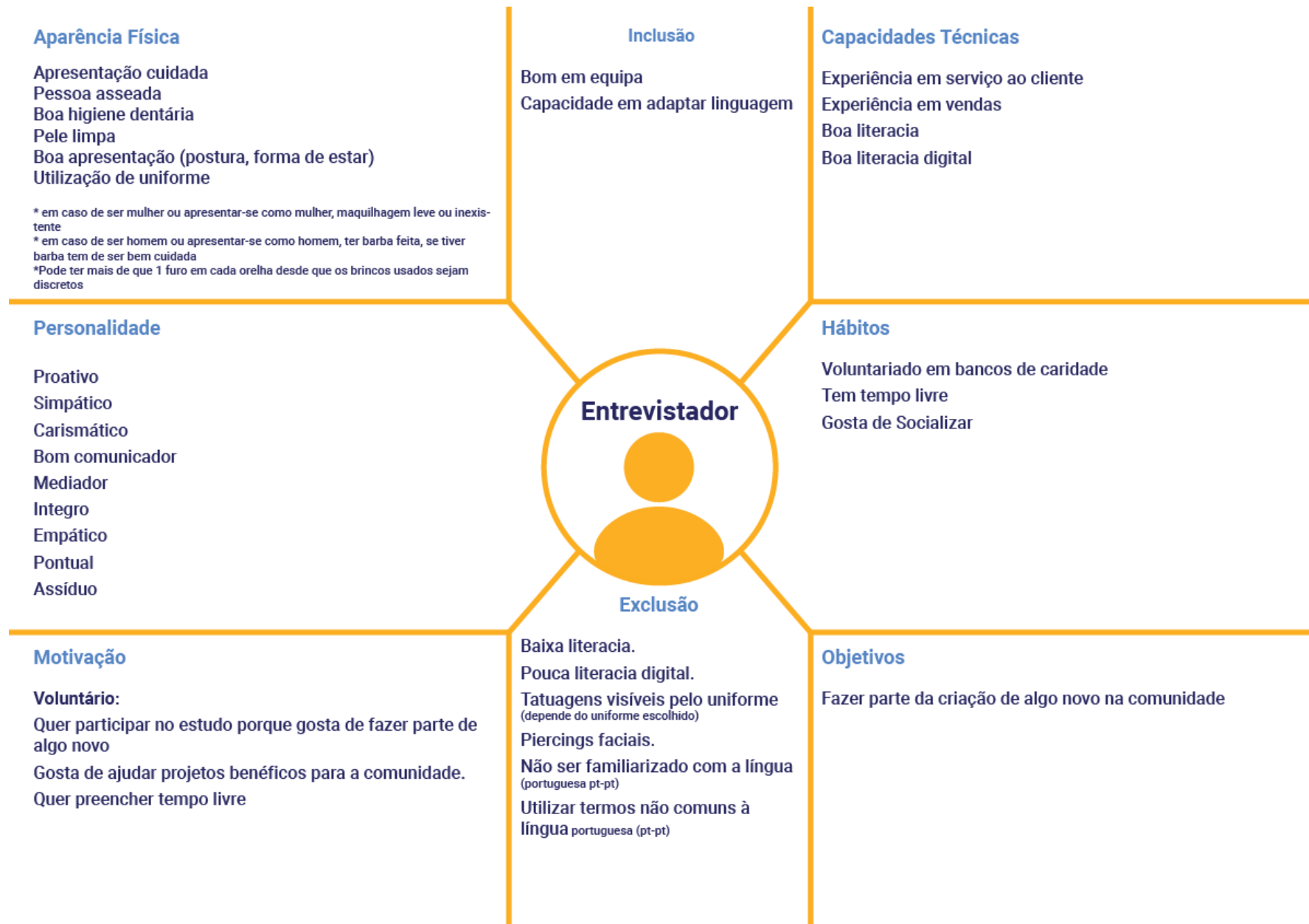
- Adapt the discourse to the team in which the designer is inserted (to avoid misunderstandings and prejudices/suppositions)
- Counselling of interviews with experts of similar studies
- Have interviews with the population that will be the target of the study.
- Select the design methodology(ies) to be applied
- Create a recognisable brand with the study team (name, symbol, signature)
- Create physical and digital media that will be used in the communication of the study
- Set up the fieldwork workshops.
- Define the sample of the interviewed population with the help of User Groups Definition method
- Define the communication strategy
- Define the ideal profiles of those who will contact the population through Personas (interviewer, team coach, supervisor)
- Develop support materials for the organisation of the study (logbook, budgets, operational plan)
- Create a manual or guide to assist in contacting the population (interviewer manual and logbook)

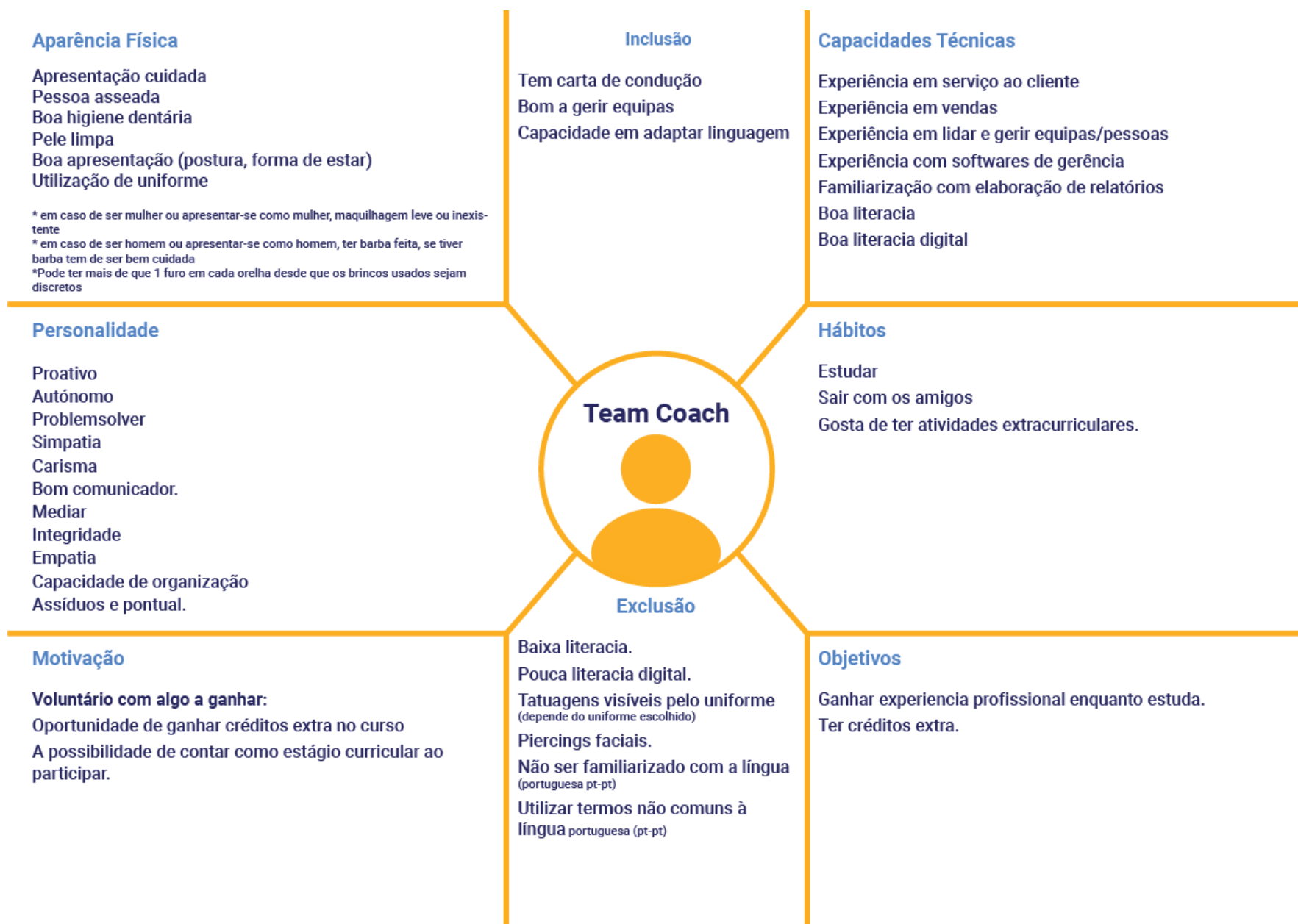
All these guidelines can be used for several cohort studies, but some topics might need adaptation to better suit the cohort study's type

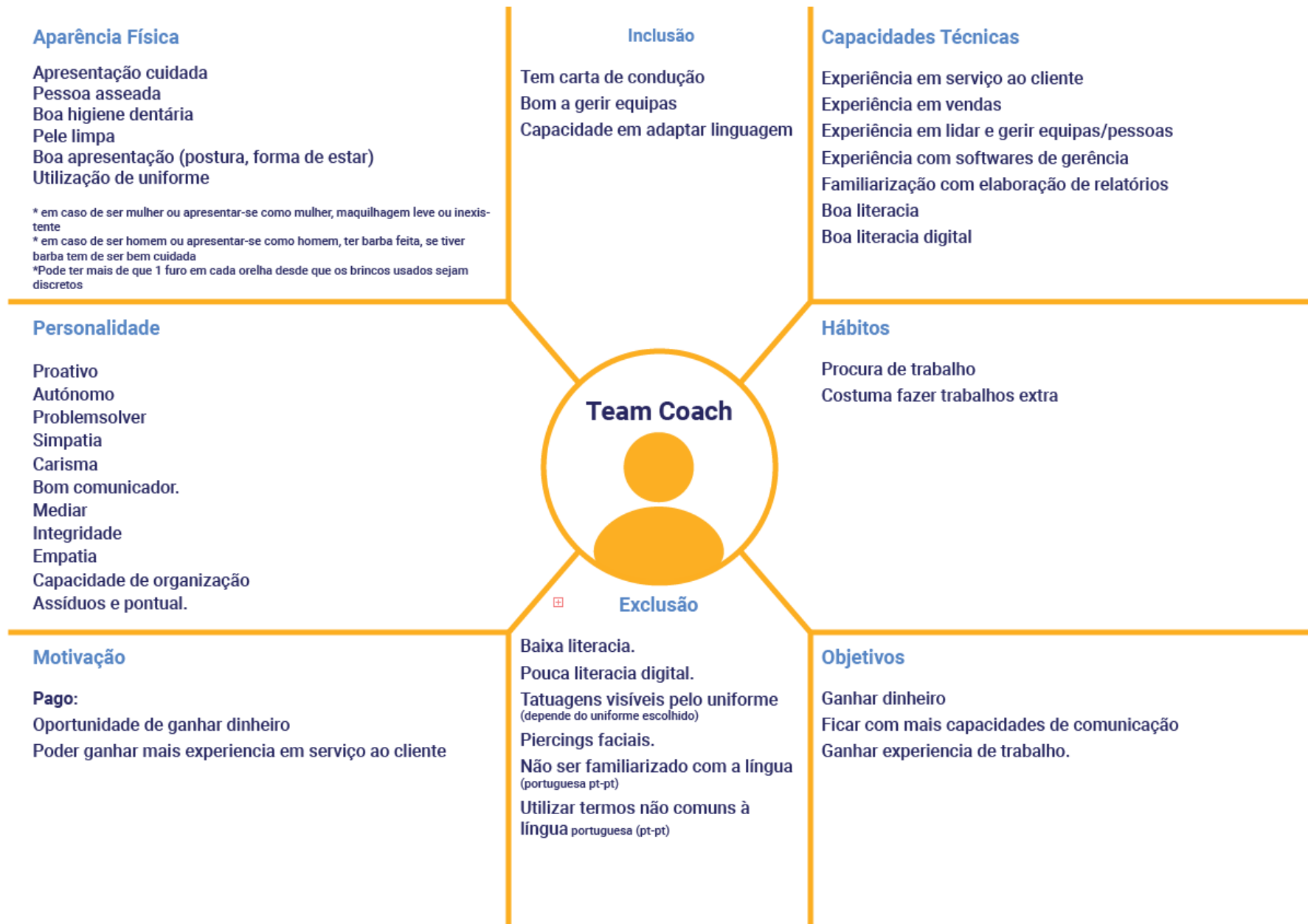
C. Personas

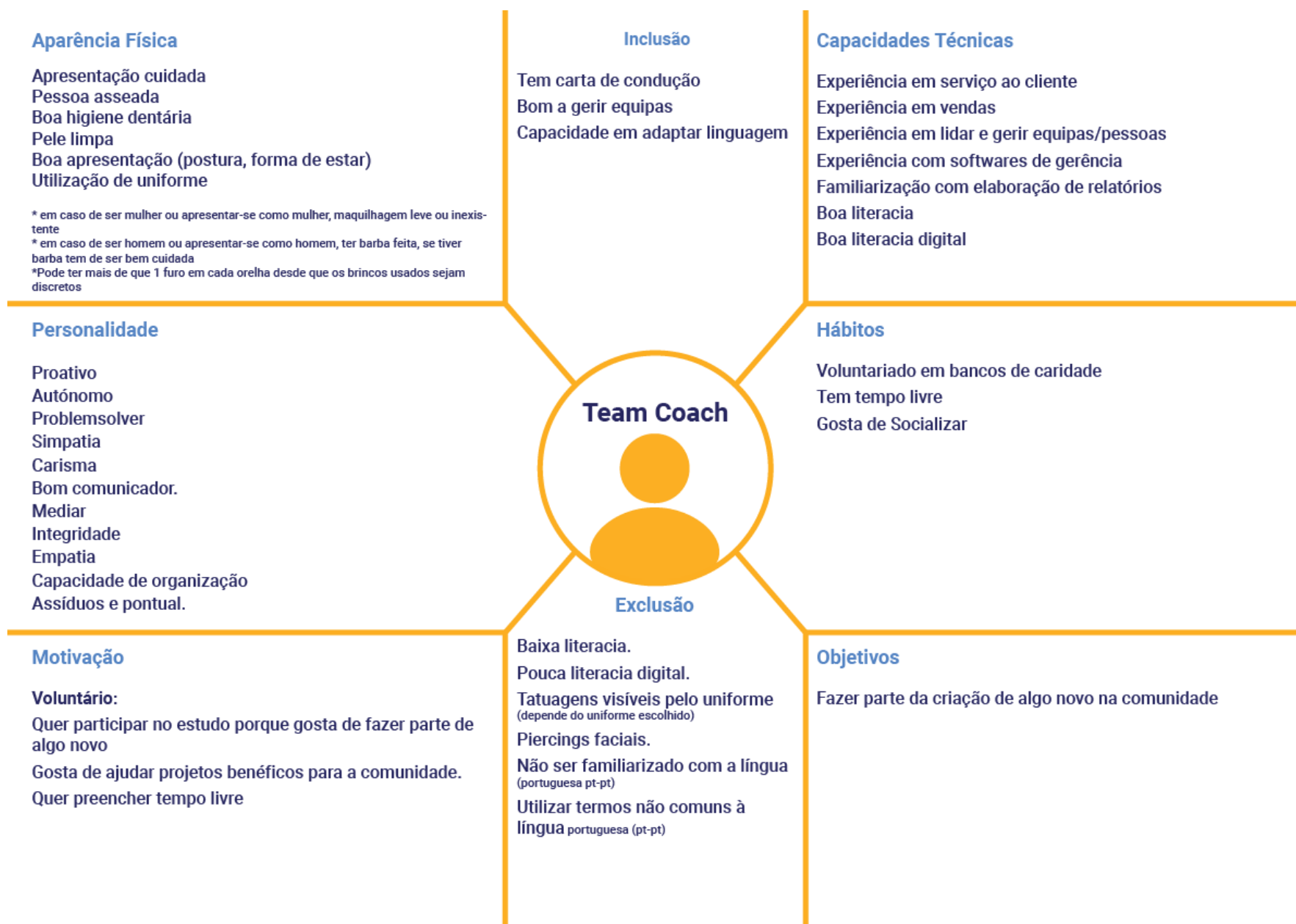


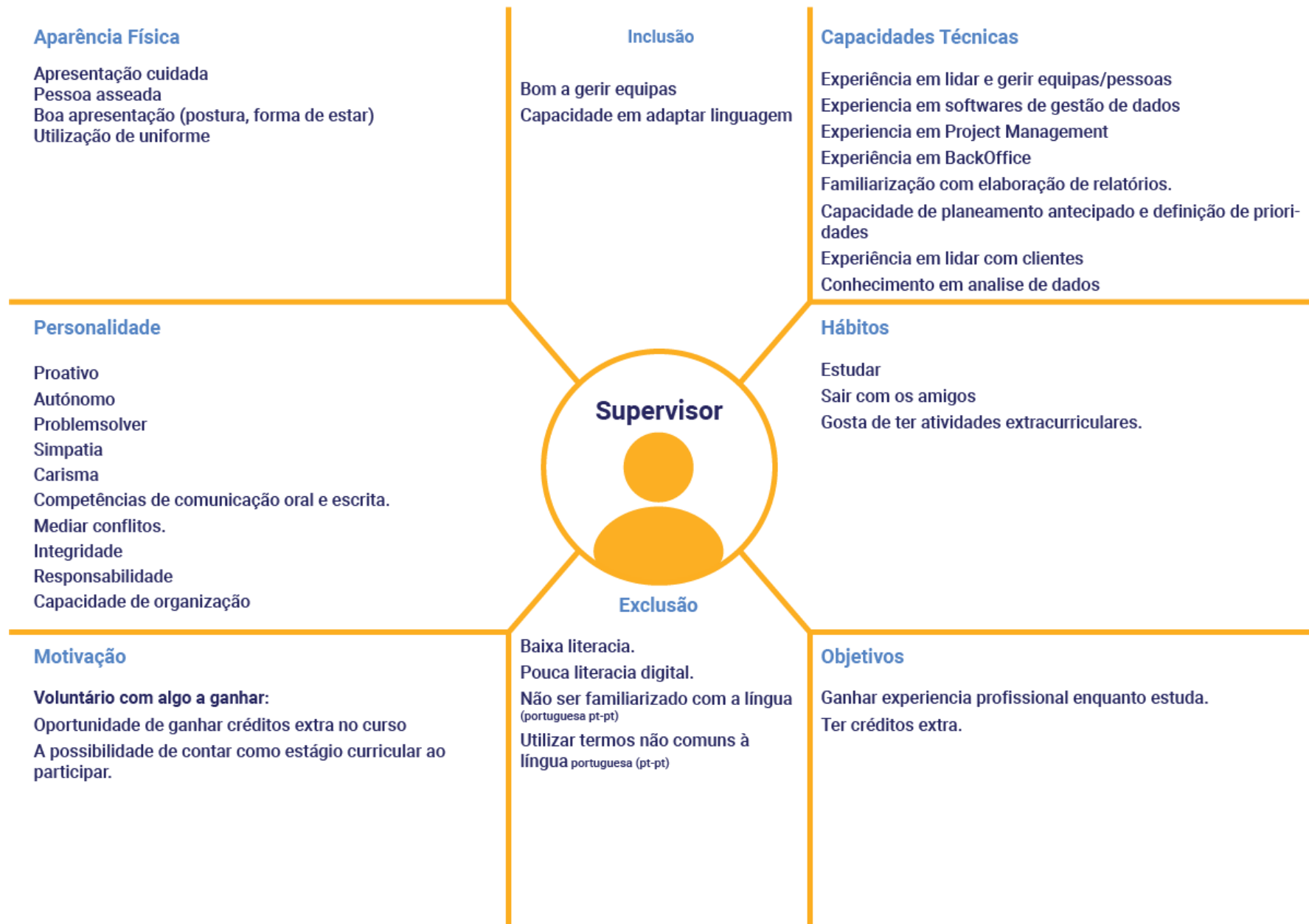


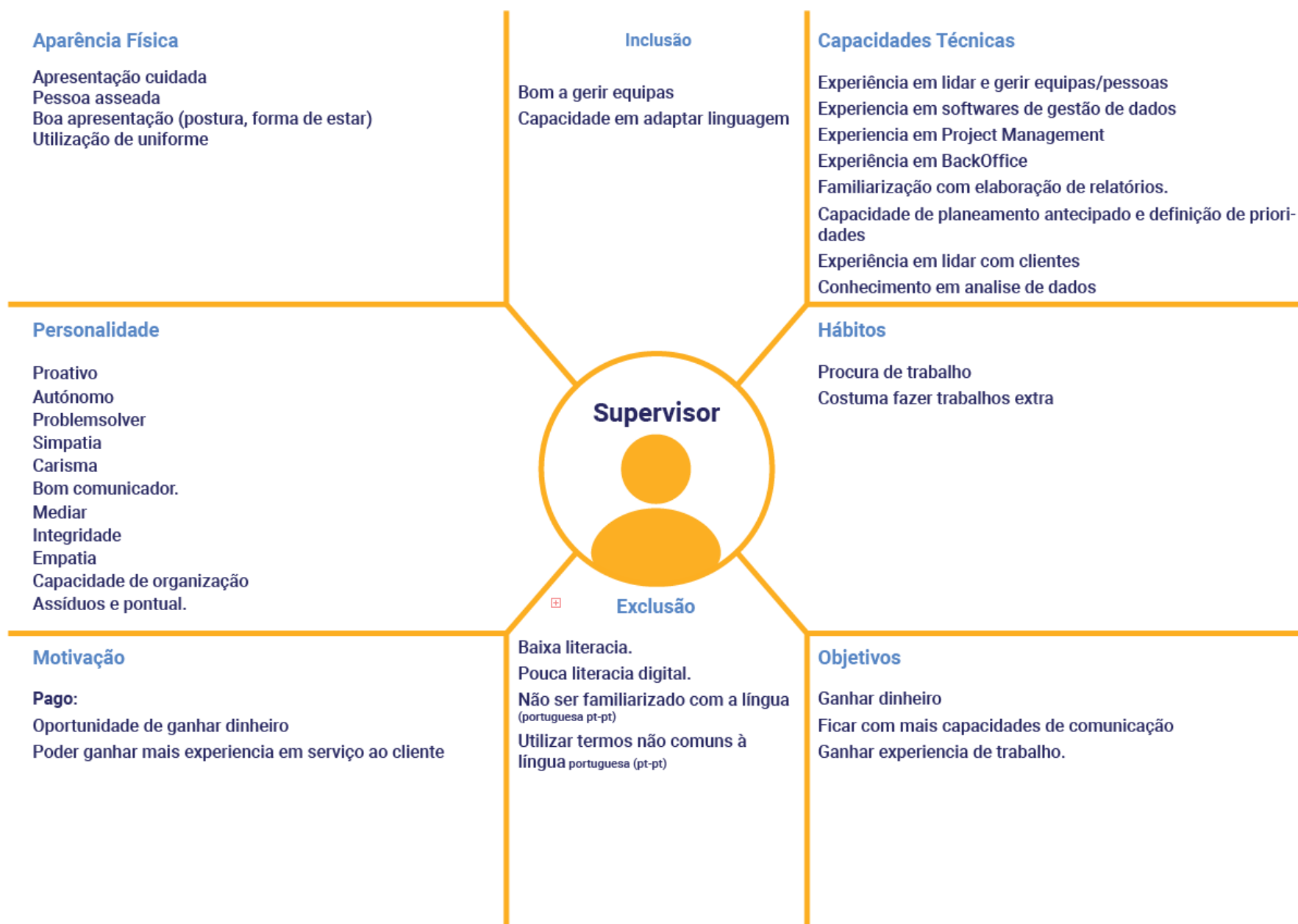


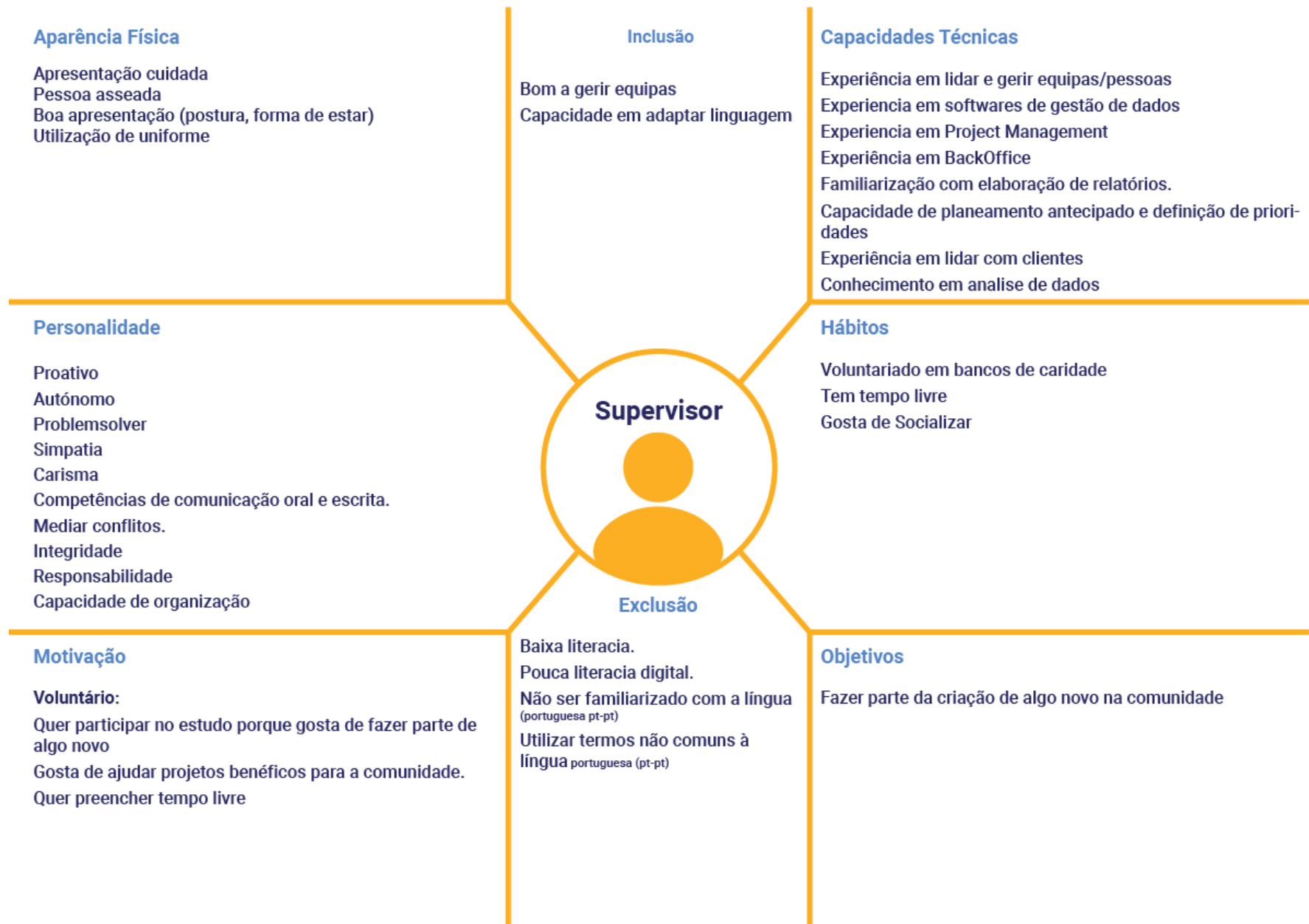












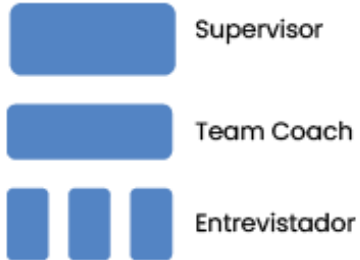
C.1 Revised personas



Resultado Do Workshop de Personas

(green and red feedback workshop)

Estrutura de equipa:



Supervisor

Responsabilidades:

Fazer a distribuição e gestão das equipas

Planificar calendários

Estatísticas semanais

Estar apto a responder a duvidas das equipas

Responder as questões e pedidos de informação por parte da população

Capacidade em gerir conflitos

Objetivos:

Manter as equipas otimizadas

Garantir a continuidade do estudo

Team Coach

Responsabilidades:

Auxiliar na deslocação da equipa

Gerir a sua equipa no campo

Capacidade em gerir conflitos

Objetivos:

Certificar-se que a interação dos entrevistadores é feita de acordo com o guião

Entrevistador

Responsabilidades:

Ponto de contacto com a população

Apresentar o estudo

Fazer o questionário

Objetivos:

Manter população focada e motivada

Resultados do workshop de personas

Entrevistador (estudante Licenciatura, Voluntário):

Personalidade:

Proativo

Simpático

Carismático

Bom comunicador

Mediador

Integro

Empático

Pontual e assíduo

Capacidades Técnicas:

Boa literacia

Boa literacia digital

Experiência em serviço ao

cliente

Experiência em vendas

Características Físicas

Apresentação cuidada

Pessoa asseada

Boa apresentação (postura, forma de estar)

Higiene dentária

Pele limpa

*em caso de ser mulher ou apresentar-se

como mulher, maquilhagem leve ou inexistente.

*em caso de ser homem ou apresentar-se

como homem, ter barba feita, se tiver barba

tem de ser bem cuidada.

*utilização de uniforme

*Pode ter mais de que 1 furo em cada orelha

desde que os brincos usados sejam discretos.

Critério de exclusão:

Baixa literacia.

Pouca literacia digital.

Não ser familiarizado com a língua portuguesa (pt-pt)

Utilizar termos não comuns à língua portuguesa (pt-pt)

Tatuagens visíveis pelo uniforme (depende do uniforme escolhido)

Piercings faciais.

Team Coach (estudante Mestrado, Voluntário):

Personalidade:

Proativo
 Autônomo
 Problemsolver
 Simpatia
 Carisma
 Bom comunicador
 Mediar
 Integridade
 Empatia
 Capacidade de organização
 Assíduos e pontual.

Características Físicas

Apresentação cuidada
 Pessoa asseada
 Boa apresentação (postura, forma de estar)
 Higiene dentária
 Pele limpa
 *em caso de ser mulher ou apresentar-se como mulher, maquilhagem leve ou inexistente.
 *em caso de ser homem ou apresentar-se como homem, ter barba feita, se tiver barba tem de ser bem cuidada.
 *utilização de uniforme
 *Pode ter mais de que 1 furo em cada orelha desde que os brincos usados sejam discretos.

Capacidades Técnicas:

Boa literacia
 Boa literacia digital
 Experiência em serviço ao cliente
 Experiência em vendas

Critério de exclusão:

Baixa literacia.
 Pouca literacia digital
 Não ter carta de condução
 Tatuagens visíveis pelo uniforme (depende do uniforme escolhido)
 Piercings faciais.
 Não ser familiarizado com a língua (portuguesa pt-pt)
 Utilizar termos não comuns à língua portuguesa (pt-pt)

Supervisor (Pago):

Personalidade:

Proativo
Autónomo
Problemsolver
Simpatia
Carisma
Competências de comunicação oral e escrita.
Mediar conflitos.
Integridade
Responsabilidade
Capacidade de organização

Capacidades Técnicas:

Experiência em lidar e gerir equipas/pessoas
Experiência em Project Management
Experiência em BackOffice
Familiarização com elaboração de relatórios.
Capacidade de planeamento antecipado e definição de prioridades
~~Experiência em lidar com clientes~~
~~Conhecimento em análise de dados~~
~~Experiência em softwares de gestão de dados~~

Características Físicas

Apresentação cuidada
Pessoa asseada
Boa apresentação (postura, forma de estar)

Critério de exclusão:

Baixa literacia.
Pouca literacia digital.
Não ser familiarizado com a língua (portuguesa pt-pt)
Utilizar termos não comuns à língua portuguesa (pt-pt)

D. Cohort challenges list presentation

Entrevistas Experts

Amostra Populacional: 4

Experts	Coortes em que participaram
Sara Dias	EpiDoC, LISA
Carla Lopes	EpiPorto, EPITeen, Geração XXI
Helena Canhão*	EpiDoC, CoReumaPT
Ana Rodrigues	EpiDoC, EpiReuma

* Entrevista inacabada, por impossibilidade de reunir.

- Necessidade de **identificação** ao abordar pessoas;
- **Financiamento para pagar aos entrevistadores** é necessário para mantê-los no estudo;
- **Compensação aos participantes** da coorte para gerar motivação e mantê-los no estudo;
- Necessidade de **formar os entrevistadores**;
- Panfletos / cartas geram **confiança**;
- **Dar feedback** aos participantes é importante;
- **Informar nas instituições** da existência do estudo;
- **Supervisor dos entrevistadores** tem de ser pago;
- Ter uma pessoa preparada para **trabalhar no backoffice**;
- Entrevistadores devem ter um **manual do entrevistador**;
- **Taxa de sucesso porta-a-porta é maior** que por telefone;
- Para obter um x de participantes foi necessário bater à porta de **10x mais pessoas**;
- **Tempo de questionário e apresentação do estudo** no máximo 30 min. presencial e 15 min. por telefone;

Entrevistas População

Amostra Populacional: 8

Género	Idade (anos)	Residência	Educação
Feminino	24	Cidade	Mestrado
Feminino	62	Rural	6º Ano
Feminino	43	Periferia	12º Ano
Feminino	55	Cidade	12º Ano
Feminino	78	Rural	4º Ano
Masculino	24	Periferia	TESP
Masculino	22	Rural	Licenciatura
Masculino	41	Cidade	Doutoramento

- Maior parte **desconhece o que é um estudo coorte**.
- Motivo de participação ganhar **mais conhecimentos em saúde**.
- Primeiro contacto por **carta ou email**.
- Publicitação em redes sociais, centros de saúde e **locais de maior afluência da região**.
- Horário de contacto ao **fim da tarde ou fins de semana** (sábados à tarde).
- Deslocação só se **não interferir com o horário de trabalho**.
- Para deslocação necessários **exames de rotina para compensar**.
- Ter acesso ao **feedback das respostas** e como isso afeta o estudo.
- **2 entrevistadores**, com aspeto cuidado e identificados (preferencialmente um homem e uma mulher).
- Estudo porta a porta pode ser dificultado pela **tipologia do edifício** (prédios ou condomínios).
- **Desconfiança inicial** dos motivos de contacto porta a porta.
- **Recompensas** como descontos culturais, estacionamento livre, ou descontos em supermercados (cupões).

Suportes de Comunicação

- Folheto (simples, gramagem média-baixa) - **40.000 unidades**
- Camisola/T-shirt com logo (estampagem) para os entrevistadores - **depende do número de entrevistadores seleccionados**
- Identificação dos entrevistadores - **depende do número de entrevistadores seleccionados**
- Cartazes A3 + A4 - **500 unidades**
- Carta + envelope - com logótipos do estudo e das instituições - **depende do número de população**
- Muppi - **Câmara Municipal de Leiria**
- Outdoor - **Câmara Municipal de Leiria**
- Cartão de participação (no fim do inquirido responder ao questionário) - **8000 unidades**
- Página alojada no Website da **Câmara Municipal de Leiria**
- **Conteúdos** para redes sociais - criação de perfis, imagens e vídeos (reels)

E. LISA – Work plan

Identificação do Projeto

Horizonte Temporal

Data de início: 2021

Data de fim: 2036

População-alvo

População adulta residente
no concelho de Leiria

18 ou mais anos à data de
início do estudo

Entidades Envolvidas

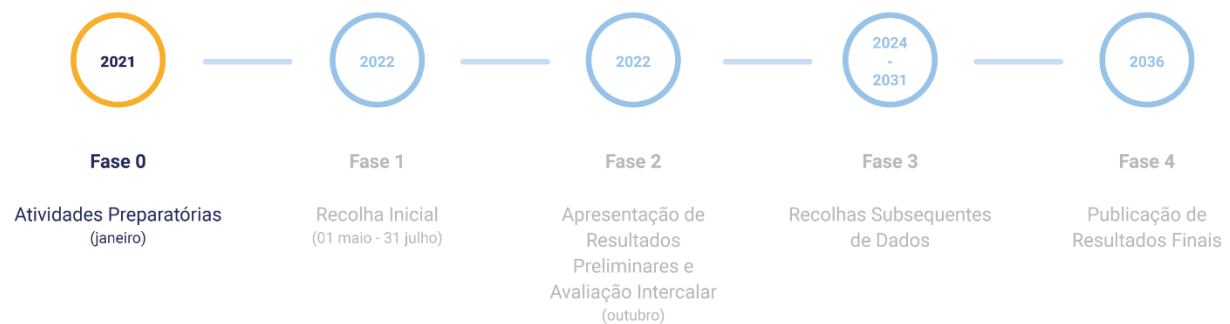
Câmara Municipal de Leiria

ACES Pinhal Litoral

Politécnico de Leiria

Centro Hospitalar de Leiria

Implementação



Equipa

Alexandre Ferreira, MD (ACES PL)
Ana Soledade (CML)
Ana Valentim (CML)
Bartolomeu Alves, MD (ACES PL)
Catarina Reis, PhD (ciTechCare/ESTG – PLeiria)
Cátia Gomes (Câmara Municipal Leiria)
Constança Rocha (estudante Mestrado Design para a Saúde e Bem Estar, LIDA/ESAD – PLeiria)
Daniela Marques (estudante Mestrado Design para a Saúde e Bem Estar, LIDA/ESAD – PLeiria)
Denise Velho, MD (ACES PL)
Elga Ferreira, PhD (LIDA/ESAD – PLeiria)
Eliana Santiago, PhD (LIDA/ESAD – PLeiria)
Estêvão Soares dos Santos, MD (ACES PL/ESAD - PLeiria)
Maria Pedro Guarino, PhD (ciTechCare/ESSLei – PLeiria)
Rui Passadouro, MD (ACES PL)
Sara Simões Dias - (ciTechCare – PLeiria)
Tiago Gabriel, MD (ACES PL)

Recursos Materiais

Comunicação do Projeto

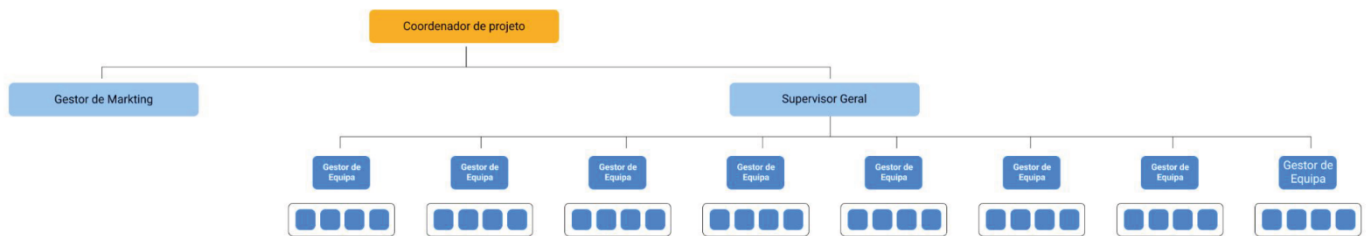
- 40.000 Folhetos (simples, gramagem média-baixa)
- 64 Camisolas/T-shirts com logo (estampagem) para os entrevistadores
- 50 Identificações para os entrevistadores.
- 150 Cartazes A3 a cores
- 350 Cartazes A4 a cores
- 10.000 Cartas (com logótipos do estudo e das instituições)
- 10.000 Envelopes (com logótipos do estudo e das instituições)
- 8000 Cartão de participação
- Muppis
- Outdoors
- Website
- Conteúdos para redes sociais

Fase 1

- Ferramenta Gestão de Projeto
- 16 tablets
- 16 routers móveis
- 4003 Consentimentos Informados
- Despesas por Deslocação

Recursos Humanos

- 1 Supervisor Geral
- 1 Gestor de Comunicação e Marketing Digital
- 8 Gestores de Equipa
- 32 Entrevistadores



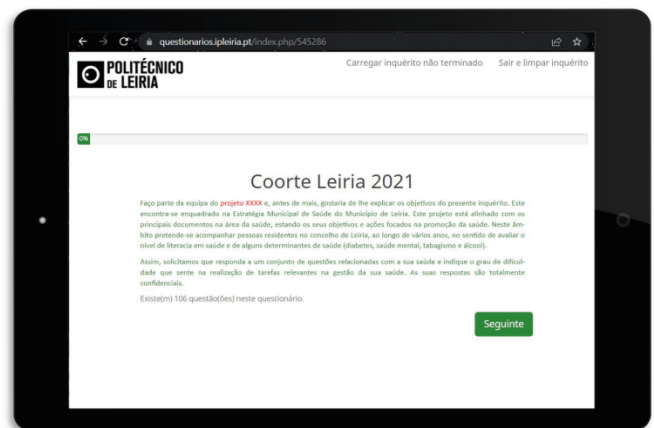
Instrumentos

Questionário

106 perguntas

Inquéritos:

- Características sociodemográficas e doença;
- FINDRISC - Escala de risco de doença metabólica;
- HLS-EU-PT - Escala de avaliação de literacia em saúde;
- FAGERSTROM - Questionário de grau de dependência tabágica;
- HADS - Questionário de ansiedade e depressão;
- AUDIT - Escala de avaliação de hábitos de consumo de álcool.



F. LISA – Brand presentation

Referências Visuais



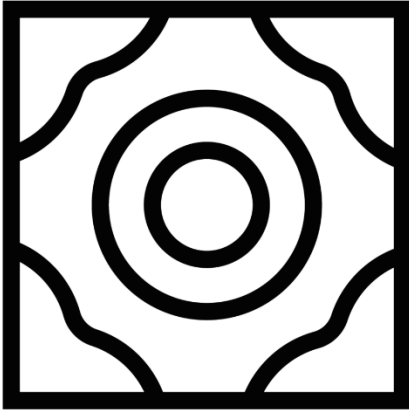
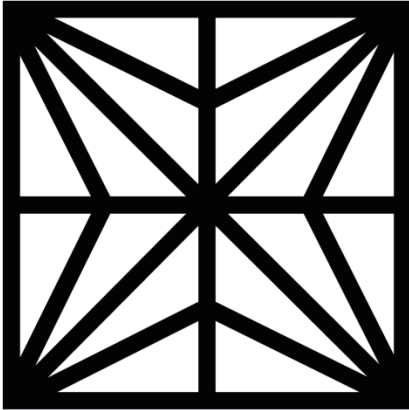
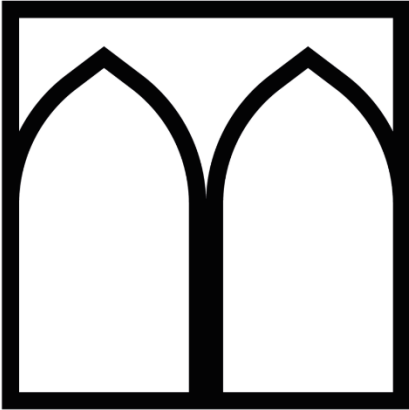
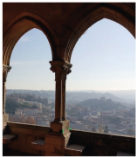
Referências Visuais



Referências Visuais



Símbolo



Paleta de Cores



Tipografia

Poppins

ABCDEFGHIJKLMNO
PQRSTUVWXYZ
abcdefghijklmno
pqrstuvwxyz
0123456789
!?=;.,“()

Source Sans Pro

ABCDEFGHIJKLMNOPQR
STUVWXYZ
abcdefghijklmnopqrstu
vwxyz
0123456789
!?=;.,“()

Source Serif Pro

ABCDEFGHIJKLMNOP
QRSTUVWXYZ
abcdefghijklmnopqrs
tuvwxyz
0123456789
!?=;.,“()

Proposta de marca

lisa

Proposta de Logótipo





Logótipo com Assinatura





G. LISA – Debut “Aldeia da Saúde”



Parceiros



Câmara Municipal de Leiria

www.cm-leiria.pt



ciTechCare
CENTER FOR INNOVATIVE
CARE AND HEALTH TECHNOLOGY



Estudo Lisa

Estudo de base
populacional com
duração de
4 anos

Recolha e análise de
dados em saúde
a cada
2 anos

Participantes

População adulta
residente no concelho de
Leiria

Indivíduos que saibam **falar**
e **compreender** a
língua portuguesa

Objetivos

1

Medir a literacia em
saúde

2

Auxiliar na planificação de
estratégias de organização de
cuidados e políticas em saúde

3

Melhorar os
cuidados de
saúde prestados

Saber
Ser
Saúde

**A participação de
todos é muito
importante!**

H. Questionnaire

D. Questionnaire

Durante o preenchimento do questionário apenas algumas perguntas podem ter ajuda no registo por parte do entrevistador. Estas ajudas vão estar destacadas a vermelho.

1. Informed Consent

Depois de ler o documento “Informação ao Participante e Formulário de Consentimento Informado para o Estudo”, declaro que compreendi as intenções deste estudo, aceito participar voluntariamente, respondendo a este questionário e permito o uso das minhas respostas para fins de investigação. Tomei conhecimento que poderei desistir a qualquer momento do preenchimento do questionário, sem que daí advinha qualquer penalização. *(Esta questão é obrigatória)*

- Terminar agora
- Prosseguir para o preenchimento do questionário

2. Sociodemographic characteristics and illness

2.1 NIF (Número de Identificação Fiscal)

Ajuda: Auxiliar na leitura do CC se necessário.

2.2 Qual o seu número de telefone/telemóvel?

2.3 Qual o seu email?

2.4 Qual o seu estado civil?

- Solteiro
- Casado
- União de facto
- Divorciado
- Viúvo

2.5 Qual o seu género?

- Feminino
- Masculino
- Outro

2.6 Que nível de escolaridade completou?

Ajuda: Se não completou por exemplo o 11º ano deve responder “Terceiro ciclo”

- Nenhum
- Primeiro ciclo (do 1º ao 4º anos)
- Segundo ciclo (5º e 6º anos)
- Terceiro ciclo (7º, 8º e 9º anos)
- Ensino Secundário (10º, 11º e 12 anos)
- Curso técnico superior profissional
- Bacharelato
- Licenciatura
- Mestrado

- Doutoramento

2.7 Nasceu no concelho de Leiria? (*resposta obrigatória*)

- Sim
- Não

2.8 Em que concelho nasceu?

2.9 Qual o rendimento mensal do agregado familiar?

Ajuda: O agregado familiar é constituído por pessoas que vivem na mesma casa e com alguma relação de parentesco.

- <500€
- 501€ - 750€
- 751€ - 1000€
- 1001€ - 1500€
- 1501€ - 2000€
- 2001€ - 2500€
- 2501€ - 3000€
- 3001€ - 4000€
- >4000€

2.10 Alguma vez o médico diagnosticou hipertensão (Tensão Arterial Alta)?

Ajuda: Pressão alta, medida com um aparelho próprio cada vez que vai ao médico.

- Sim
- Não

2.11 Alguma vez o médico diagnosticou colesterol ou triglicéridos elevados?

Ajuda: Níveis de gordura no sangue, medidos a partir de análises ao sangue.

- Sim
- Não

2.12 Alguma vez o médico diagnosticou uma doença pulmonar?

Ajuda: Por exemplo, asma, pneumonia, bronquite, bronquiolite, tuberculose, apneia do sono, doença pulmonar obstrutiva crónica (DPOC), enfisema pulmonar, doenças intersticiais, fibrose cística, embolia pulmonar, hipertensão pulmonar, displasia broncopulmonar e cancro do pulmão.

- Sim
- Não

2.13 Alguma vez o médico lhe diagnosticou uma doença do coração?

Ajuda: Por exemplo, insuficiência cardíaca, aterosclerose, arritmias, cardiomiopatia e hipertensão arterial.

- Sim
- Não

2.14 É fumador?

- Nunca fumei
- No passado fumei
- Sim, diariamente
- Ocasionalmente fumo

2.15 Há quantos anos é que fuma?

2.16 Que produtos tabágicos consome atualmente?

- Cigarro de maço
- Cigarro de enrolar
- Cigarilha de maço

- Cigarilha de enrolar
- Tabaco de mascar
- Cachimbo
- Charuto
- Tabaco aquecido
- Cigarro eletrónico (vape)
- Cachimbo de água/shisha
- Outro: _____

3. HLS-EU-PT - Escala de avaliação de literacia em saúde

As seguintes questões pretendem avaliar a literacia em saúde, ou seja, a capacidade de aceder, compreender e utilizar a informação em saúde.

Nesta secção o entrevistador não deve interferir em momento algum nas respostas dadas pelo inquirido. Deve ser evitada toda a ajuda possível para que as respostas não sejam influenciadas pelos comentários do entrevistador.

3.1 Encontrar informação sobre tratamento de doenças que o/a preocupam?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.2 Saber mais sobre onde obter ajuda especializada quando está doente?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.3 Compreender o que o seu médico lhe diz?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.3 Compreender as instruções do seu médico ou farmacêutico sobre a toma do medicamento que foi receitado?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.4 Avaliar quando pode necessitar de uma segunda opinião de outro médico?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.5 Usar a informação que o seu médico lhe dá para tomar decisões sobre a sua doença?

Seguir as instruções do seu médico ou farmacêutico?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.6 Encontrar informação para lidar com os problemas de saúde mental como o stress ou a depressão?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.7 Compreender os avisos de saúde relativos a comportamentos como fumar, falta de atividade física e excesso de álcool?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.8 Compreender porque precisa de fazer rastreios? *Como por exemplo mamografias, papanicolau, pesquisa de sangue nas fezes*

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.9 Avaliar se a informação nos meios de comunicação sobre os riscos para a saúde é de confiança?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.10 Decidir como se pode proteger da doença com base em informação dos meios de comunicação?

Ajuda: Como por exemplo mamografias, papanicolau, pesquisa de sangue nas fezes.

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.11 Saber mais sobre as atividades que são boas para o seu bem-estar mental?

- Muito Difícil

- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.12 Compreender conselhos sobre saúde vindos de familiares ou amigos?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.13 Compreender a informação nos meios de comunicação como se manter mais saudável?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

3.14 Avaliar quais os comportamentos diários que estão relacionados com a sua saúde?

- Muito Difícil
- Difícil
- Fácil
- Muito Fácil
- Não Sei

4. Consentimento Informado

Muito obrigada por ter respondido ao questionário sobre a Literacia em Saúde. A nossa entrevista já vai a meio, contudo ainda não terminou. De seguida vamos pedir-lhe que responda ao questionário sobre saúde mental, deseja continuar a responder?

- Sim
- Não

5. HADS - Questionário de ansiedade e depressão

Este questionário foi construído para ajudar a saber como se sente. Pedimos-lhe que selecione a resposta que melhor descreve a forma como se tem sentido na última semana. Não demore muito tempo a pensar nas respostas. A sua reação imediata a cada questão será provavelmente mais correta do que uma resposta muito ponderada.

5.1 Sinto-me tenso/a ou nervoso/a:

- Quase sempre
- Muitas vezes
- Por vezes
- Nunca

5.2 Ainda sinto prazer nas coisas de que costumava gostar:

Ajuda: Por exemplo, rotina do dia a dia, ir ao café com amigos/família, praticar atividades físicas, passar tempo com quem mais gosta, passear, ir ao cinema, ...

- Tanto como antes
- Não tanto agora

- Só um pouco
- Quase nada

5.3 Tenho uma sensação de medo, como se algo terrível estivesse para acontecer:

Ajuda: Tem receio de fazer algumas coisas, sente-se ameaçado, tanto fisicamente como psicologicamente?

- Sim e muito forte
- Sim, mas não muito forte
- Um pouco, mas não me aflige
- De modo algum

5.4 Sou capaz de rir e ver o lado divertido das coisas:

- Tanto como antes
- Não tanto como antes
- Muito menos agora
- Nunca

5.5 Tenho a cabeça cheia de preocupações:

Ajuda: Está sempre preocupado com alguma coisa, não consegue parar de pensar nos seus problemas e isso acaba por prejudicar o seu dia a dia.

- A maior parte do tempo
- Muitas vezes
- Por vezes
- Quase nunca

5.6 Sinto-me animado/a:

- Nunca
- Poucas vezes
- De vez em quando
- Quase sempre

5.7 Sou capaz de estar descontraidamente sentado/a e sentir-me relaxado/a:

- Quase sempre
- Muitas vezes
- Por vezes
- Nunca

5.8 Sinto-me mais lento/a, como se fizesse as coisas mais devagar:

- Quase sempre
- Muitas vezes
- Por vezes
- Nunca

5.8 Fico de tal forma apreensivo/a (com medo), que até sinto um aperto no estômago:

Ajuda: Sente náuseas, por vezes vontade de vomitar, dor no estomago, ou até refluxo.

- Nunca
- Por vezes
- Muitas vezes
- Quase sempre

5.9 Perdi o interesse em cuidar do meu aspecto físico:

Ajuda: Cuidar da sua aparência física, isto pode envolver praticar desporto, fazer uma alimentação equilibrada e saudável, ter bons hábitos de higiene, cuidar da sua pele e cabelo, e ainda dedicar algum tempo na escolha do que vai vestir para se sentir bem.

- Completamente
- Não dou a atenção que devia
- Talvez cuide menos que antes
- Tenho o mesmo interesse de sempre

5.10 Sinto-me de tal forma inquieto/a que não consigo estar parado/a:

Ajuda: Sente-se agitado, desassossegado, não consegue parar quieto...

- Muito
- Bastante
- Não muito
- Nada

5.11 Penso com prazer nas coisas que podem acontecer no futuro:

- Tanto como antes
- Não tanto como antes
- Bastante menos agora
- Quase nunca

5.12 De repente, tenho sensações de pânico:

Ajuda: Sente o coração a bater mais rápido, tremores, falta de ar, dor no peito ou desconforto, medo, vertigens, sensação de dormência, náuseas, entre outros sintomas.

- Muitas vezes
- Bastantes vezes
- Por vezes
- Nunca

5.13 Sou capaz de apreciar um bom livro ou um programa de rádio ou televisão:

- Muitas vezes
- De vez em quando
- Poucas vezes
- Quase nunca

6. Consentimento Informado

Muito obrigada por ter respondido ao questionário sobre a Saúde Mental. A nossa entrevista já vai a mais de meio, contudo ainda não terminou. De seguida vamos pedir-lhe que responda ao questionário sobre Doença Metabólica, deseja continuar a responder?

- Sim
- Não

7. FINDRISC - Escala de risco de doença metabólica

As seguintes questões pretendem avaliar alguns parâmetros relativos ao risco de diabetes tipo II.

7.1 Qual a sua data de nascimento?

7.2 Qual é o seu peso (em kg)?

Ajuda: Não necessita de se pesar no momento, registe mais ou menos o que pesava da última vez.

7.3 Qual a sua altura (em centímetros)?

Ajuda: Pode ser a que está no CC.

7.4 Algum membro da sua família tem diabetes? *Membro da família: Considerar mãe, pai e irmãos*

Ajuda: Pais, irmãos, avós, tios ou primos. Namorados e maridos não contam.

- Sim
- Não

7.5 Um membro da sua família tem diabetes. É afastado ou próximo?

- Membro próximo da família: pai, mãe, filho, irmão, irmã.
- Membro afastado: avô, tia, tio, primo...

7.6 Qual é a sua medida abdominal, ao nível do umbigo?

Ajuda: Tem que ser medido o mais próximo da pele. Se o inquirido tem uma peça de roupa fina vestida, não é necessário despir. Posicionar uma fita métrica ao redor da barriga, mais precisamente sobre o umbigo. Se for necessário o entrevistador pode auxiliar neste processo.

7.7 Pratica pelo menos 30 minutos de atividade física por dia? *Considerar atividade física se for incluída em jogos recreativos, desporto, exercício planeado, deslocações (andar, pedalar) e tarefas ocupacionais ou domésticas que obriguem a atividade continuada, no mínimo, por 30 minutos.*

- Sim
- Não

7.8 Costuma comer legumes e frutas?

- Todos os dias
- Nem sempre

7.9 Toma medicamentos para a hipertensão?

Ajuda: Pressão/tensão alta. Medicação prescrita pelo seu médico.

- Sim
- Não

7.10 Alguma vez descobriu que tinha a taxa de açúcar no sangue elevada?

Ajuda: Tem diabetes? Também conhecida como glicose. Pode ser medida via análise sanguínea ou por meio de medidores e aparelhos de glicémia de fácil utilização e que a própria pessoa pode usar.

- Sim
- Não

8. Consentimento Informado

Muito obrigada por ter respondido aos questionários anteriores. A nossa entrevista está quase a terminar. De seguida vamos pedir-lhe que responda ao questionário sobre estilos de vida: álcool, deseja continuar a responder?

- Sim
- Não (comentário que o não, não vai para o fim do questionário)

9. AUDIT - Escala de avaliação de hábitos de consumo de álcool

As seguintes questões pretendem avaliar hábitos de consumo de álcool.

9.1 Com que frequência consome bebidas que contêm álcool?

- Nunca
- Uma vez por mês ou menos
- 2 a 4 vezes por mês
- 2 a 3 vezes por semana
- 4 ou mais vezes por semana

9.2 Quando bebe, quantas bebidas contendo álcool consome num dia normal?

Ajuda: Quantos copos?

- 1 ou 2
- 3 ou 4
- 5 ou 6
- De 7 a 9
- 10 ou mais

9.3 Com que frequência consome seis bebidas ou mais numa única ocasião?

- Nunca
- Uma vez por mês ou menos
- 2 a 4 vezes por mês
- 2 a 3 vezes por semana
- 4 ou mais vezes por semana

9.4 Nos últimos 12 meses, com que frequência se apercebeu de que não conseguia parar de beber depois de começar?

- Nunca
- Uma vez por mês ou menos
- 2 a 4 vezes por mês
- 2 a 3 vezes por semana
- 4 ou mais vezes por semana

9.5 Nos últimos 12 meses, com que frequência não conseguiu cumprir as tarefas que habitualmente lhe exige, por ter bebido?

Ajuda: Não conseguiu ir trabalhar, levar os seus filhos à escola, faltou a algum compromisso, ...

- Nunca
- Uma vez por mês ou menos
- 2 a 4 vezes por mês
- 2 a 3 vezes por semana
- 4 ou mais vezes por semana

9.6 Nos últimos 12 meses, com que frequência precisou de beber logo de manhã para “curar” uma ressaca?

Ajuda: Precisou de beber porque estava com dor de cabeça forte, sensibilidade ao som e à luz, enjoos e vômitos, mal-estar geral, dores no corpo, boca seca e muita sede.

- Nunca
- Uma vez por mês ou menos
- 2 a 4 vezes por mês
- 2 a 3 vezes por semana
- 4 ou mais vezes por semana

9.7 Nos últimos 12 meses, com que frequência teve sentimentos de culpa ou de remorsos por ter bebido?

Ajuda: Sentiu-se arrependido por ter bebido? Se pudesse voltar atrás teria feito de forma diferente?

- Nunca
- Uma vez por mês ou menos
- 2 a 4 vezes por mês
- 2 a 3 vezes por semana
- 4 ou mais vezes por semana

9.8 Nos últimos 12 meses, com que frequência não se lembrou do que aconteceu na noite anterior por ter bebido?

- Nunca
- Uma vez por mês ou menos
- 2 a 4 vezes por mês
- 2 a 3 vezes por semana
- 4 ou mais vezes por semana

9.9 Já alguma vez ficou ferido ou alguém ficou ferido por você ter bebido?

Ajuda: Já alguém se magoou porque você estava bêbado? Resultado de uma queda, de um confronto físico, ou até mesmo porque conduziu alcoolizado?

- Não
- Sim, mas não nos últimos 12 meses
- Sim, aconteceu nos últimos 12 meses

9.10 Já alguma vez um familiar, amigo, médico ou outro profissional de saúde manifestou preocupação pelo seu consumo de álcool ou sugeriu que deixasse de beber?

- Não
- Sim, mas não nos últimos 12 meses
- Sim, aconteceu nos últimos 12 meses

10. Consentimento informado

Muito obrigada por ter respondido aos questionários anteriores. A nossa entrevista está quase a terminar, só nos falta um questionário sobre estilos de vida: tabaco, deseja continuar a responder?

- Sim
- Não

11. Questionário de FAGERSTROM

As seguintes questões pretendem avaliar hábitos de consumo de tabaco.

11.1 Actualmente fuma?

- Sim
- Não

11.2 Quanto tempo depois de acordar fuma o seu primeiro cigarro?

- ≤ 5 min
- 6-30 min
- 31-60 minutos
- > 60 min

11.3 Custa-lhe não fumar em locais onde é proibido?

- Sim
- Não

11.4 Qual o cigarro que seria mais difícil para si deixar de fumar?

- O primeiro da manhã
- Qualquer outro

11.5 Quantos cigarros fuma por dia?

- 10 ou menos
- 11-20
- 21-30

- 31 ou mais

11.6 Fuma mais nas primeiras horas depois de acordar ou no resto do dia?

- Nas primeiras horas depois de acordar
- No resto do dia

11.7 Se estiver muito doente, de cama, fuma ou não?

- Sim
- Não

12. Final

Muito obrigada pela sua colaboração!

I. Interview informed consent

**Centro de Inovação em Tecnologias e Cuidados de Saúde (ciTechCare) Politécnico
de Leiria**

Leiria Coorte

Estudo da literacia em saúde na população adulta residente no concelho de Leiria

Informação ao Participante e Formulário de Consentimento Informado para o Estudo

14 de Dezembro de 2021

Documento: Informação ao Voluntário e Formulário de Consentimento Informado

**ESTE DOCUMENTO É COMPOSTO DE 08 PÁGINAS E FEITO EM DUPLICADO: UMA VIA PARA O
INVESTIGADOR, OUTRA PARA A PESSOA QUE CONSENTE.**



1. Porque recebi este documento para ler?

É convidado(a) a participar voluntariamente numa entrevista informal com o objetivo de representar a população de Leiria, testando um questionário pertencente ao estudo coorte e respondendo a algumas questões. Esta fase antecede o estudo coorte que tem como objetivo avaliar a literacia em saúde na população adulta residente no concelho de Leiria ao longo dos próximos 10 anos. Este estudo é conduzido por uma equipa de Cientistas, Médicos Especialistas, Engenheiros, Enfermeiros, Designers e Técnicos.

Este documento de informação e formulário de consentimento informado dá-lhe todos os dados sobre o estudo e entrevista para os quais está a ser convidado(a). Por favor, leia atentamente as informações e discuta-as com quem desejar. Em caso de dúvidas, fale com um elemento da equipa de investigação do estudo para que este esclareça as mesmas.

A sua decisão de participar é voluntária. Isto significa que:

- É livre de decidir participar, ou não participar, na entrevista informal;
- Pode interromper a entrevista em qualquer altura e sem indicar um motivo;

2. Qual a finalidade deste estudo?

Em Portugal a promoção da literacia em saúde dos cidadãos tem sido, nas últimas décadas, identificada como o caminho para a melhoria dos cuidados de saúde e assumida como uma preocupação na definição de políticas de saúde. Isto porque diferentes estudos têm demonstrado que um nível inadequado de literacia em saúde pode ter implicações significativas nos resultados em saúde, na utilização dos serviços de saúde e, conseqüentemente, nos gastos em Saúde. Como tal, a equipa de investigação está a desenvolver um estudo de coorte, prospetivo, longitudinal que irá decorrer nos próximos 10 anos e que tem como objetivo medir a literacia em saúde da população adulta residente no concelho de Leiria.

Este estudo irá decorrer nas 18 freguesias de Leiria em parceria com o Agrupamento de Centro de Saúde (ACES) Pinhal Litoral, Câmara Municipal de Leiria e com o centro de investigação Centro de Inovação em Tecnologias e Cuidados de Saúde (ciTechCare) do Politécnico de Leiria.

2.1. Quanto tempo irá durar a minha participação?

A entrevista informal conta com uma série de 25 perguntas e um questionário, sendo que o tempo de participação depende do desenvolvimento na resposta dada pelo entrevistado. A estimativa de duração desta entrevista está entre 1 hora e 1 hora e meia.

3. O que irá acontecer se eu participar nesta entrevista informal?

Caso aceite participar nesta entrevista informal, primeiro tem que assinar o consentimento informado. Depois passamos à sessão de perguntas e de teste, que serão gravados em vídeo e áudio para futura consulta.

4. O que acontece aos meus dados pessoais?

Este estudo está a ser promovido no estrito cumprimento das disposições legais e regulamentos aplicáveis, nomeadamente pelo Regulamento Geral de Proteção de Dados na sua atual redação, bem como pelos requisitos internacionais das Boas Práticas Clínicas. A equipa de investigação substituirá o seu nome e outras informações pessoais, exceto a idade/data de nascimento e o sexo por, por um código numérico, tornando



tais dados anónimos. Esse código será associado à informação do estudo, de modo a que seja improvável alguém conseguir identificá-lo(a).

4.1. Onde são guardados e protegidos os dados pessoais?

Os seus dados pessoais recolhidos no âmbito deste estudo e partilhados com o Politécnico de Leiria, a Câmara Municipal de Leiria e ACES Pinhal Litoral serão mantidos em arquivos seguros, com acesso restrito, sejam eles eletrónicos ou físicos, de acordo com a legislação guardados por 5 (cinco) anos após a conclusão do estudo. Após terminado o período obrigatório de conservação destes, os mesmos serão totalmente destruídos. Os parceiros de investigação que colaboram neste estudo não estão autorizados a partilhar os seus dados com terceiros.

Os dados que o(a) identificam diretamente, nomeadamente a lista que liga o seu NIF ao código numérico que lhe foi atribuído, é mantida apenas pelo(a) Investigador(a) Responsável do estudo em local seguro e só este poderá aceder à sua identidade. Esta lista ficará em formato eletrónico e não será feita qualquer cópia da mesma. Todos os ficheiros eletrónicos terão restrição de permissão de acesso aos conteúdos, impedindo que as informações confidenciais sejam acedidas, impressas, reencaminhadas ou copiadas por pessoas não autorizadas. A sua identidade não será revelada em quaisquer relatórios ou publicações resultantes do estudo.

4.2. Quem pode ver os meus dados pessoais?

Os dados pessoais sobre si serão mantidos de forma protegida pela equipa do estudo, através de codificação dos dados que o identifiquem, e só estarão acessíveis às seguintes pessoas ou entidades: aos investigadores da equipa, às Comissões de Ética competentes, às Autoridades de Saúde, a outras entidades competentes ao abrigo do disposto na legislação. Todas as pessoas ou entidades com acesso aos seus dados pessoais estão sujeitas a sigilo profissional.

4.3. Para que são utilizados os meus dados pessoais?

Os seus dados pessoais serão combinados e analisados com os dados pessoais de todos os participantes da entrevista, para que possamos obter o máximo de informação possível sobre os objetivos do estudo de coorte de Leiria. Na publicação dos resultados deste estudo a sua identidade nunca será revelada.

4.4. Quais são os seus direitos específicos quanto aos seus dados pessoais?

De acordo com o artigo 13º do Regulamento Geral de Proteção de Dados (RGPD), tem o direito de, através de um(a) investigador(a) envolvido no estudo, consultar os seus dados pessoais e de solicitar alterações aos mesmos (artigos 16º e 19º do RGPD), caso não estejam corretos. Cabe ao responsável pelo tratamento fornecer ao titular uma cópia dos dados pessoais em fase de tratamento (artigo 15º do RGPD). Durante o estudo, tem o direito de retirar o seu consentimento de participação o que implica que deixe de participar no estudo. Tem o direito de requerer que os seus dados sejam transmitidos para uma terceira pessoa por si designada (artigo 20º do RGPD). Tem o direito de se opor ao tratamento dos dados pessoais a qualquer momento (artigo 21º do RGPD) e de solicitar o apagamento dos seus dados pessoais, embora apenas quando os dados em questão não forem mais necessários para a finalidade para a qual foram recolhidos (artigos 17º a 19º do RGPD). Caso tenha dúvidas sobre a recolha e utilização de informações sobre si, ou caso pretenda exercer os direitos que possa ter relativamente a esta informação, deve contactar um elemento da equipa do estudo.

Caso sinta que os seus direitos de privacidade não foram respeitados pode apresentar uma queixa junto da Comissão Nacional de Proteção de Dados e tem o direito a exigir uma indemnização como consequência do processamento ilícito das suas informações pessoais.



5. Como posso obter mais informações?

Durante a sua participação, se tiver perguntas ou dúvidas sobre o mesmo ou algum problema relacionado com o estudo, com os seus direitos relativamente aos seus dados pessoais, com o tratamento dos seus dados, por favor contacte:

Sara Simões Dias (*Investigadora*)

Centro de Inovação em Tecnologias e Cuidados de Saúde (ciTechCare)
Rua de Santo André – 66-68, Campus 5, Politécnico de Leiria
2410-541 Leiria – Portugal
Telefone: (+351) 244 845 300
Telemóvel: (+351) 917 479 381
E-mail: marlene.c.lages@ipleiria.pt

Dra. Ana Maria Pratas dos Reis (*Encarregado de Proteção de Dados do Politécnico de Leiria*)

Instituto Politécnico de Leiria
Rua General Norton de Matos
2411-901 Leiria
E-mail: dpo@ipleiria.pt

Se tiver dúvidas relativamente à proteção dos seus dados pessoais, ou caso considere que os seus direitos de privacidade foram violados, deve contactar:

Comissão Nacional de Proteção de Dados

Avenida D. Carlos I, 134 – 1.º
1200-651 Lisboa
Telefone: (+351) 213 928 400
Fax: (+351) 213 976 832 E-mail:
geral@cnpd.pt

Se tiver dúvidas sobre os seus direitos enquanto participante num estudo, deve contactar:

Comissão de Ética para a Investigação Clínica

Avenida do Brasil, nº53 – Pavilhão 17-A
1749-004 Lisboa
Telefone: (+351) 217 985 340
Fax: (+351) 211 117 544 E-mail:
ceic@ceic.pt

Comissão de Ética da Administração Regional de Saúde do Centro

Sede e Conselho Direto
Alameda Júlio Henriques S/n, Apartado 1087
3001-553 Coimbra
Telefone: (+351) 239 796 800
Fax: (+351) 239 796 861
E-mail: secretariado.ca@arscentro.min-saude.pt



8. Página de Assinaturas

Protocolo nº e Versão: PI.NC.EC.2020.01 versão 02, outubro de 2020

Título: Coorte Leiria: Estudo da literacia em saúde na população adulta residente no concelho de Leiria

Eu, _____, natural de _____, concordo em participar na entrevista informal e testagem de questionário que antecedem o estudo “Coorte Leiria: Estudo da literacia em saúde na população adulta residente no concelho de Leiria”. Li este documento, explicaram-me o seu conteúdo e esclareci todas as minhas dúvidas com o(a) investigador(a). Compreendi o objetivo deste estudo, o que envolve a minha participação e o que me irá acontecer. Aceito voluntariamente participar nesta fase do estudo, tal como me foi descrito por este documento, tendo a possibilidade de, em qualquer momento, recusar participar sem qualquer tipo de consequência. Confirmando que recebi uma cópia assinada deste documento de Informação ao Participante e Formulário de Consentimento Informado.

Ao assinar este documento, autorizo a utilização, acesso e partilha dos meus dados clínicos, que de forma voluntária forneço, com garantias de confidencialidade e anonimato que me são dadas pelo investigador(a).

Este consentimento é válido exceto e até que seja por mim revogado.

Participante	
Nome do(a) participante (em maiúsculas)	
Assinatura do(a) participante	Data

Investigador(a)	
Nome do(a) investigador(a) (em maiúsculas)	
DANIELA MARQUES CONSTANÇA ROCHA	
Assinatura do(a) investigador(a)	Data

9. Consentimento para a realização de investigações adicionais com os dados pessoais

Durante o estudo ou após a sua conclusão, o Politécnico de Leiria gostaria de poder utilizar os seus dados recolhidos no âmbito deste projeto de investigação para projetos médicos e/ou científicos de investigação adicionais, desde que autorizados previamente por uma Comissão de Ética competente. Os dados pessoais



incluem a idade/ano de nascimento, sexo, um código numérico que o(a) identifica, informações do estudo, conforme explicado na Secção “O que acontece aos meus dados pessoais?”. Estes projetos de investigação adicionais podem incluir estudos para adquirir mais conhecimentos relacionados com a literacia em saúde, ansiedade e depressão, risco metabólico e tabagismo. Isto irá permitir que o Politécnico de Leiria e outras instituições de investigação possam promover a realização de ações de educação para a saúde na população mais personalizadas. A informação no âmbito da Secção “O que acontece aos meus dados pessoais?” também está relacionada com este consentimento opcional.

Não tem que aceitar a utilização dos seus dados pessoais para investigações adicionais. Se optar por permitir que o Politécnico de Leiria use os seus dados pessoais para investigações adicionais pode mudar a sua decisão, em qualquer altura. Se decidir que já não quer que o Politécnico de Leiria seja autorizado a utilizar os seus dados para investigações adicionais pode fazê-lo sem ter de mudar o seu consentimento inicial, para participação no estudo. Deve informar um elemento da equipa de investigação do estudo se for esse o caso.

Ao assinar este consentimento, concordo com a utilização dos meus dados pessoais em investigações adicionais, conforme acima descrito.

Este consentimento é válido exceto e até que seja por mim revogado.

Participante	
Nome do(a) participante (em maiúsculas)	
Assinatura do(a) participante	Data

Investigador	
Nome do(a) investigador(a) (em maiúsculas)	
DANIELA MARQUES	CONSTANÇA ROCHA
Assinatura do(a) investigador(a)	Data

J. Leiria's population distribution

This document was exported from INE (National Statistical Office), and is presented in its original language (Portuguese).

Período de referência dos dados	Local de residência (à data dos Censos 2021)	População residente (N.º) por Local de residência (à data dos Censos 2021), Sexo e Grupo etário; Decenal														
		Sexo														
		HM					H					M				
		Grupo etário														
		Total	0 - 14 anos	15 - 24 anos	25 - 64 anos	65 e mais anos	Total	0 - 14 anos	15 - 24 anos	25 - 64 anos	65 e mais anos	Total	0 - 14 anos	15 - 24 anos	25 - 64 anos	65 e mais anos
N.º	N.º	N.º	N.º	N.º	N.º	N.º	N.º	N.º	N.º	N.º	N.º	N.º	N.º	N.º		
2011	Leiria	126 884	19 316	14 556	70 978	22 034	61 310	9 920	7 468	34 291	9 631	65 574	9 396	7 088	36 687	12 403
	Amor	4 747	739	498	2 622	888	2 384	407	266	1 330	381	2 363	332	232	1 292	507
	Arrabal	2 684	388	296	1 422	578	1 328	190	167	706	265	1 356	198	129	716	313
	Bajouca	2 004	318	265	1 051	370	1 021	167	143	543	168	983	151	122	508	202
	Bidoeira de Cima	2 250	360	226	1 177	487	1 113	196	113	583	221	1 137	164	113	594	266
	Caranguejeira	4 691	704	558	2 490	939	2 282	362	276	1 231	413	2 409	342	282	1 259	526
	Coimbrão	1 735	196	199	895	445	853	102	102	456	193	882	94	97	439	252
	Maceira	9 901	1 338	1 054	5 474	2 035	4 831	666	530	2 718	917	5 070	672	524	2 756	1 118
	Milagres	3 071	463	376	1 702	530	1 522	242	192	865	223	1 549	221	184	837	307
	Regueira de Pontes	2 221	322	256	1 233	410	1 097	177	123	609	188	1 124	145	133	624	222
	União das freguesias de Colmeias e Memória	4 085	499	460	2 007	1 119	1 923	258	221	979	465	2 162	241	239	1 028	654
	União das freguesias de Leiria, Pousos, Barreira e Cortes	31 775	4 805	3 625	18 313	5 032	15 040	2 435	1 880	8 619	2 106	16 735	2 370	1 745	9 694	2 926
	União das freguesias de Marrazes e Barosa	24 684	4 221	2 767	14 381	3 315	11 812	2 190	1 401	6 737	1 484	12 872	2 031	1 366	7 644	1 831
	União das freguesias de Monte Real e Carvide	5 756	827	589	3 162	1 178	2 754	417	299	1 531	507	3 002	410	290	1 631	671
	União das freguesias de Monte Redondo e Carreira	5 564	826	685	3 061	992	2 741	427	350	1 519	445	2 823	399	335	1 542	547
União das freguesias de Parceiros e Azoia	6 940	1 091	778	4 052	1 019	3 365	544	392	1 970	459	3 575	547	386	2 082	560	
União das freguesias de Santa Catarina da Serra e Chainça	4 870	712	694	2 600	864	2 409	368	382	1 282	377	2 461	344	312	1 318	487	
União das freguesias de Santa Eufémia e Boa Vista	4 072	603	497	2 200	772	1 986	314	253	1 071	348	2 086	289	244	1 129	424	
União das freguesias de Souto da Carpalhosa e Ortigosa	5 834	904	733	3 136	1 061	2 849	458	378	1 542	471	2 985	446	355	1 594	590	

População residente (N.º) por Local de residência (à data dos Censos 2021), Sexo e Grupo etário; Decenal - INE, Recenseamento da população e habitação - Censos 2021

