POLITÉCNICO DE LEIRIA | ESCOLA SUPERIOR DE ARTES E DESIGN

Cohort Study Good Practices:
Design Guidelines for a Preparatory Stage

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To my family,
to those with whom I share blood,
and to those which whom I share my unconditional love,
thank you for all the support and for making me believe this was possible!

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The author informs that there are several papers written, presented in conferences, and published concerning the work undertaken on this project, some of which are mentioned throughout this dissertation. Here is a full list about those:

- **Poster** publication 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: Constança Netto-Rocha; Daniela S. Marques
- **Article in press** and **presentation** in **EhSemi2022 Seminário de estudantes em tecnologias digitais e saúde/ bem-estar** (conference 3rd Feb 2022 – University of Aveiro) - "Design Approaches: Health Literacy capacitation in the County of Leiria" Authors: Daniela S. F. Marques; Constança I.F.P. Netto-Rocha
- **Article published and presentation** in **Conference on Applied Human Factors and Ergonomics (AHFE 2022)** (conference 24th to 28th Jul 2022 - New York) - "Cohort Study Good Practices: Design Communication and Capacitation Processes" Authors: Elga Ferreira, Eliana Penedos-Santiago, Constança Netto-Rocha, Daniela Sofia Marques, Estêvão Soares dos Santos, Sara Simões Dias
- **Article published and presentation** in **ECADE The European Conference on arts, Design & Education** (conference 7th to 10th Jul 2022 – University of Porto) - "The role of Design in Health Observational Studies" Authors: Daniela F. Marques; Constança Netto-Rocha
- **Article published** as preprint - "Design Communication Processes in the LISA Cohort Study" Authors: Constança Netto-Rocha; Daniela Sofia Marques
- **Poster published** in **XL Reunión Anual de la Sociedad Espanola de Epidemiologia, XVII Congresso da Associação Portuguesa de Epidemiologia** (conference 30th Aug to 2nd Sep 2022, San Sebastian) – "LISA – ESTUDO DE COORTE DA LITERACIA EM SAÚDE" Authors: Sara Simões Dias, Estêvão Soares Santos, Bartolomeu Alves, Tiago Gabriel, Constança Netto-Rocha, Daniela Sofia Marques, Rui Passadouro.

The author would also like to acknowledge that due to protection of data and personal information of interviewees the interviews aren't attached to this dissertation.

Abstract

Low health literacy is recognized as one of the most important predictors of poor health outcomes, with a stronger effect than age, race, income, employment status or education level. In Leiria's county, it is speculated that an appreciable part of the population's morbidity and poor health habits might be attributable to low health literacy. However, no formal studies were conducted to explore this hypothesis. To address it, institutions in Leiria such as the City Hall, Polytechnic of Leiria and ACES Pinhal Litoral decided to conduct a longitudinal and prospective cohort study, where a sample of the population is followed throughout time to understand if their choices regarding health and lifestyle habits are indeed affected by their health literacy levels. The choice for a cohort study is associated with the ongoing process of "improving literacy", bringing out the interest to know about people's health literacy currently, and in a future time (10 years). Also, the institutions involved are planning to study, gather more information, and to apply some interventions that aim to improve health literacy, being this type of study the most suitable since it allows them to see if those interventions are having the desired effect (improvement of population's health literacy).

Focused on the preparatory part of this cohort study, this project aims to improve the communication effectiveness between these parts in the county of Leiria, interviewers and population, to avoid common cohort problems, such as: 1) gathering a suitable number of participants that can represent the population; 2) follow-up maintenance of participants; 3) keeping the interviewers and participants engaged with the study, after the first contact.

The first step of this project is the development and creation of a distinctive brand, whose identity can be maintained throughout all its communication and dissemination media, so that the population can identify, the cohort study to which it refers and awaken their curiosity to participate.

Towards addressing the cohort studies problems, mentioned above, capacitation processes were applied, oriented by Service Design and Participatory Design methodologies, such as, informal interviews and user group definition, that helped in the comprehension of the study and also allowed the creation of personas to characterize the interviewers of the cohort study and the population. This supported the formation of archetypes that were studied on how different communication techniques and strategies work. To complement, workshops were conducted to understand how the chosen interviewers interact, preparing them to adapt their communication when facing people from different generations, education, and social backgrounds.

By carrying out this project simultaneously with the cohort study, it's possible to evaluate, over time, how the design methodologies can empower and facilitate communication and intervene, changing tactics in case it's needed. Additionally, since there's a lack of information about the way the preparatory phase of cohort studies is designed, it was also envisaged the creation of guidelines that can be replicated in future cohort studies that can take place in other communities, cities, or even other countries.

Keywords: Cohort Study, Guidelines, Good Practices, Capacitation, Service Design, Participatory Design

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List of 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	Center 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 Arts
LISA	Longitudinal Study of Health Literacy in the county of Leiria

1. Introduction

The idea of doing a dissertation related to a cohort study's preparatory stages steamed from an invitation from a multidisciplinary team that was highly motivated to create a cohort study focused on health literacy in the county of Leiria. The team was composed mainly by professionals related to health and well-being fields. By adding designers[1] to the team, they were expecting to be assisted in the communication of said cohort study. Besides strengthening the interactions between the stakeholders and population of Leiria, the designers for health and well-being identified and pursued different motivations and objectives. To achieve those, it was crucial to first, perceive the specifics of cohort studies and how they operate; and after that, understand where and how this specialization of design fit in.

Cohort studies typically characterized as observational investigations that monitor a group of individuals over a defined period of time. The present dissertation seeks to delve into the subject of cohort studies and elucidate their significance in the scope of research. It is noteworthy, however, that cohort studies come in various types and are classified based on the approach adopted by the research team. In the context of this study, it is employed a closed prospective (from present to future) cohort study design, whereby the multidisciplinary team is tasked with the preparation, data collection, and selection of the population sample. This information reveals that the designers involved in this cohort study's preparation phase are part of the decision-making team, raising the following research question:

"Can design tools/resources/strategies, co-developed with healthcare professionals, researchers and population samples create useful opportunities in cohort study decision-making?"

To better grasp this research question, it is beneficial to first clarify the specialization of Design for Health and Well-being briefly. Primarily, it is a recent addition to Portugal's design specializations and there is not much information available about the role a designer can play on the various health fields, only that it is a way to bridge "Health and

[1] Me, my colleague Constança Netto-Rocha and our dissertations' supervisors.

Well-being" with "Design". Throughout this dissertation I commit myself to explain this connection and its value, while keeping in mind that it is somewhat intertwined with a large variety of other design and communication areas, being its permanent focus on health and well-being the biggest differentiation. Thus, a designer for health and well-being can be briefly described as someone that can use creative design approaches and methodologies, and application of knowledge to aid different types of organizations, institutions, or services to improve health and well-being, change lifestyle behaviours or allow a better experience of a well-defined audience (D. F. Marques & Netto-Rocha, 2022).

Regarding this specific cohort study, and following the description above, a set of methods from Service Design, User-Centered Design and Participatory Design methodologies were applied. From Service Design, "Interviews", "User Groups Definition" and "Personas"[2] methods were chosen. Regarding the User-Centered Design and Participatory Design methodologies, the design team selected "Usability Testing" and "Workshops" methods to aid the multidisciplinary team on the preparation and planning of the cohort study. These methods and methodologies allowed me to formulate the following research hypothesis, (which I expect to confirm):

> "Service Design and Participatory Design strategies assist healthcare professionals and researchers in the preparatory phase of cohort studies."

In this context, it is useful to realize that the gathering of information on cohort studies and the position of design in health is key to understanding the structure of this dissertation's work and all the stages it has gone through. Also, it is not only important to review the literature considering these themes, but to talk and transfer some knowledge about cohort studies and the connections it has with design, being that the reason why we decided to work towards the creation of guidelines.

[2] Detailed information about this method can be found in the master's dissertation of Constança Netto-Rocha.

2. Cohort Studies

According to Setia (2016) a cohort study is a type of nonexperimental or observational study. The name "cohort" derives from the Latin word "cohors", and was adopted into the epidemiology field for the first time by W. H. Frost in 1935, describing a group of people that are observed over a period of time (Hulley et al., 2007; Setia, 2016; Song & Chung, 2010). In these studies, the group is followed by a team of researchers from the moment of exposure until the presence of an outcome (Hammoudeh et al., 2018; Setia, 2016), providing information between these stages and being chosen when it is not feasible to perform studies in another practical and ethical way (Hammoudeh et al., 2018). Since the design of cohort studies is usually extended, taking years to access the outcomes, they can be considered longitudinal observational studies (Hammoudeh et al., 2018).

Cohort Studies can be categorized by the methodology used through follow-ups. A cohort is considered closed if the participants reunited in the beginning of the study are the only ones being followed until the end of the investigation (Vandenbroucke et al., 2007). On the other hand, it is considered an open cohort if the population is dynamic, entering and leaving the cohort throughout time (Vandenbroucke et al., 2007). Besides this, a cohort study can also be divided in two categories, depending on the approach to gather data: Prospective Cohort Studies and Retrospective Cohort Studies [Figure 2.1]. Considering this is a Prospective Cohort Study it will be the focus of this dissertation.

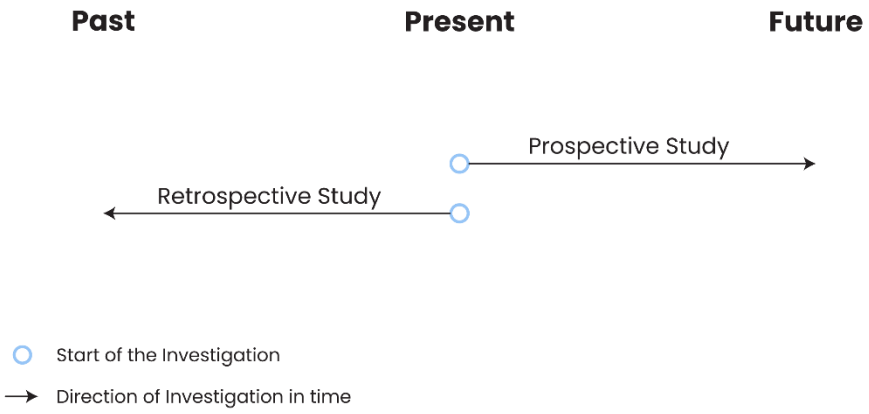


Figure 2.1 Graphic representation of the **subtypes of Cohort Studies according to their approach. Adapted figure from (Song & Chung, 2010, fig. 2).**

2.1. Prospective Studies

A prospective cohort study [Figure 2.1], as the name implies, is a type of cohort study that starts in the present, where the investigator defines the sample and the variables to be measured, and continues over time by following and studying the population, in order to observe outcomes (Hulley et al., 2007; Song & Chung, 2010). Depending on the selection of the outcome of interest, it can occur only once or multiple times (Setia, 2016). As an example, if the study's team considers the long-term effects of smoking on lung function (in a group of individuals) as the outcome of interest, it may appear multiple times, since the lung function can be assessed numerous times over several years to determine the impact of smoking on lung health over time. On the other hand, an example of a single outcome can be, if the study is about the association between maternal smoking during pregnancy and the risk of low birth weight in new-borns, then the outcome the researcher is looking for (low birth weight) can be measured only once.

The design of this type of cohort studies is described by Hulley (2007, p. 99) as "a powerful strategy for assessing incidence (number of cases of a condition in a specified time interval)". This reflects the accuracy with which is possible to measure the variables, maintaining a controlled observation of both exposures and results simultaneously, if needed (Setia, 2016,). Adding to this, another advantage of a prospective cohort study is the possibility of providing a very strong scientific evidence, since the exposure is identified by the researcher before the outcome, allowing to assess more information and to discover the causality, between the first – exposure –, and the second – outcome (Song & Chung, 2010,).

2.2. Challenges

It's important to understand that a cohort study is not usually advised for the follow-up of rare outcomes (Setia, 2016; Song & Chung, 2010), given that there is a necessity to look for both exposition to an agent that can cause illness and its dosage (i.e. tabaco) and the outcome (i.e. lung cancer), needing a longer process for their detection. With this, and despite having many advantages, cohort studies - in particular, prospective ones - entail some challenges, related to the duration of the study, the costs, the number of participants and their follow-up. These challenges or 'difficulties' need to be taken in consideration when analysing and interpreting the outcomes of the study (Hammoudeh et al., 2018).

Looking at a prospective study, and denoting that there are no data on the chosen variables prior to the study - something that happens in a retrospective design - it requires a longer duration and dedication from the team to gather the data with quality in first hand, and consequently becomes more costly (Setia, 2016). Another factor that can lead to additional costs is the possibility of carrying out more follow-ups than anticipated, or even the need to change previously chosen variables (Hulley et al., 2007). The **Figure 2.2** shows the correlation between validity and cost in different observational studies.

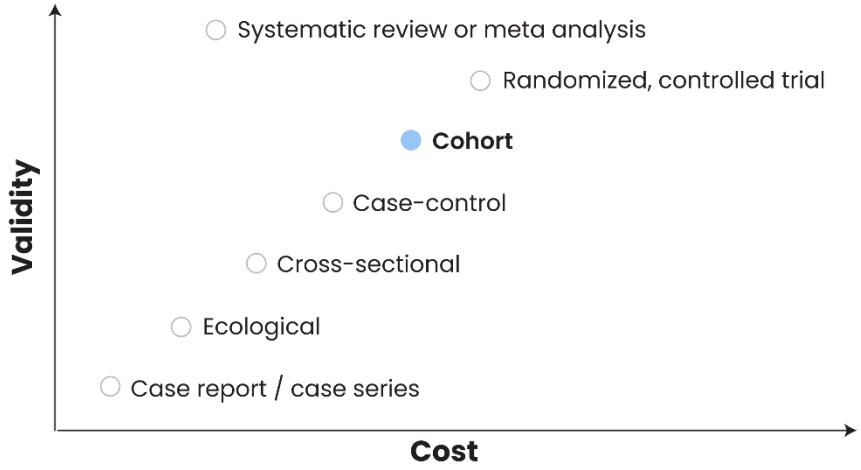


Figure 2.2 Graphic representation of the correlation between validity and cost in different observational studies. Adapted figure from (Bovbjerg, 2020, figs. 9–10).

By requiring a longer duration on the cohort study, it is crucial to consider that the follow-up of the participants will also be longer, bringing the importance of selecting "subjects that can be followed for the entire duration of the cohort study" (Song & Chung, 2010, p. 4). This significance is accompanied by the necessity of having a larger population sample, since there is always a high probability of losing participants from one phase of the study to the next, which is known as 'loss to follow-up' (Song & Chung, 2010).

Loss to Follow-up

> "Loss to follow-up is a situation in which the investigator loses contact with the subject, resulting in missing data."(Song & Chung, 2010, p. 3)

According to Hammoudeh (2018), follow-up loss cannot be greater than 20% in cohort studies, otherwise it can compromise the internal and external validity of the study. This may lead to differential loss between the exposed and un-exposed group, that can compromise the results (Hammoudeh et al., 2018).

Additionally, Kristman et al., (2004) defends that even during the planning of a cohort study – during the preparatory phase – the loss to follow-up should be taken into account, preparing and leaving available enough resources to have the number of participants in the next follow-up. To prevent this loss, there are some actions that can be previously taken by the cohort study's team. Hulley (2007) identified some of these actions and compiled them in a table [Table 2.1].

Table 2.1 "Strategies for Minimizing Losses during Follow-up" adapted from Hulley (2007, p. 105) and Song & Chung (2010, p. 15).

During enrolment
Exclude individuals that will probably be lost • Planning to move • Won't commit to study • Have diseases or morbidities unrelated to the study
Collect information for future follow-up • Subject contacts (i.e. mailing addresses, telephone numbers, and email addresses) • Social security or health number* • Contacts from the physician* • Contacts of family members or close friends, who do not reside with the individual*
During follow-up
Maintain periodic contact • By telephone: may require calls during the weekends and/or evenings • By mail: repeated mailings by e-mail or with stamped, self-addressed return envelopes • Other: newsletters or token gifts with study logo
For those not reached by phone or email contact • Contacting friends, family, or doctors • Search for addresses through other public sources* • Collect information from the hospital* • Find death certificate information through the government portal*
At all times
Respect the subject
Treat them with kindness and empathy
Help the subject understand the research question - they will be willing to contribute to making the study a success

* At this point it is necessary to take into consideration the data protection policies that exist on different countries. In case of sensitive data, an informed consent validated by an ethics committee must be used.

So, to minimize follow-up loss is important to have a connection point between the cohort study and the participants. But this is not enough, it is necessary that the team uses these

contacts, even if sometimes it requires to spend a lot of time, dedication and recurrent efforts (Hulley et al., 2007). The **Table 2.1** also informs that maintaining contact with the population during the analysis time - when there are no scheduled moments for data collection - allows the creation of a relationship of proximity and trust between participants and the study, and more precision in documenting the outcomes (Hulley et al., 2007).

Validity

> "Validity is the epidemiological assessment to the lack of systematic error."
> (Hammoudeh et al., 2018, p. 15)

The validity of a study, whether it is a cohort study or another observational study, is essential, since it provides information on the reliability of the data collected. For this there are two types of validity: internal validity and external validity.

Internal validity is related to deductions that may occur regarding the study methodologies and the way it was conducted (Bovbjerg, 2020). In other words, it is in this stage that the researcher and his team reach conclusions about what really happened during the cohort study (Hulley et al., 2007), evaluating whether the chosen methods and measurements were performed accurately - following the intended plan – regardless of random error (Hammoudeh et al., 2018). If a study has internal validity this means the conclusions of the study regarding the sample studied are true.

External validity, or generalizability, refers to the possibility to generalize results of the study to a larger population (Bovbjerg, 2020; Hammoudeh et al., 2018). This is possible when the study participants are representative of a generalized population, allowing the possibility of replicating the study, and even deducting a result that can be applied to other populations, in other conditions, and other occasions (Hammoudeh et al., 2018; Hulley et al., 2007).

These two types of validation are co-dependent and related to the follow-up loss and other bias[3]. Firstly, it is necessary that a study has internal validity to assess its external validity (Bovbjerg, 2020; Hammoudeh et al., 2018). For the latter to occur, is crucial to have

[3] This topic will be further explained on section **Bias and Confounding** .

participants that can represent the population, something that can be achieved by using a random selection method (Hammoudeh et al., 2018). If the study has internal validity but has suffered many losses during the follow-ups – selection bias –, it can influence the external validity, depending on the research question (Bovbjerg, 2020; Hammoudeh et al., 2018). For example, if the question is linked to behaviour and other abstract conditions – which are widely different on a socio-economic and demographic level – then the representativeness becomes really important (Bovbjerg, 2020).

Additionally, the loss of follow up and its correlation with internal validity will always depend on the type of participants that the cohort study loses (Fronteira, 2021). As another example, if all the participants lost are seniors, then that loss will cause a bias and affect the internal validation. In contrast, if the loss of follow up is random, and without any pattern (i.e., the cohort study reduces randomly the sample of population due of low budget) then the compliance with internal validity will not be impacted since no bias occurred. Although, if the follow-up loss reaches high numbers, then the external validity may be compromised (Fronteira, 2021).

Bias and Confounding

> "Bias is a systematic deviation of a study's result from a true value."
> (Vandenbroucke et al., 2007, p. 1636)

Just like the aforementioned issues, bias may happen in any and all types of observational studies - including cohort studies –, since all the studies involve humans and as stated by Bovbjerg (2020, p. 68) "humans are inherently biased". Therefore it is necessary to be vigilant from the very beginning of the study, because errors can occur during the planification, implementation or analysis phase, and then there's nothing the study team can do capable of correcting them (Hammoudeh et al., 2018; Vandenbroucke et al., 2007).

According to Vandenbroucke et al., (2007, p. 1636) "bias arises from flawed information or subject selection so that a wrong association is found". This citation, besides enlightening about the existence of a misleading connection between variables, informs that there are several types of bias occurring – sometimes simultaneously – in a study. The main categories of these 'errors' are: selection bias, information bias and confounding (Hammoudeh et al., 2018).

Selection bias, as aforementioned[4] can impact the internal and external validity of any type of study (Bovbjerg, 2020). Typically, it impacts the internal validity of the study (Vandenbroucke et al., 2007), however is important to note that there are also prejudices on the study's external validity, and those can only be controlled as long as the inherent limitations are understood (Bovbjerg, 2020). Within this bias category one can still find different types of systematic errors, which are associated with people's actions:

- **Response bias** – can affect the prevalence and incidence of the study, and arises when the people who answer the study and those who refuse have significative differences (i.e., if only healthy people answer a survey in one specific region, then the study will inform that there are no unhealthy people from that region) (Vandenbroucke et al., 2007).

- **Interviewer bias** – occurs if the interviewer (intentionally or not) collects information selectively. This can happen because of their knowledge about the hypotheses of the study, their desires to have a successful study, or because they weren't trained to be impartial.(Song & Chung, 2010; Vandenbroucke et al., 2007)

- **Attrition or follow-up bias** – is directly related to the loss to follow-up, and happens when people dropout of the study or die (something that might appear in long duration studies, as a prospective cohort study)(Hammoudeh et al., 2018).

- **Information bias –** also known as observation bias, classification bias or misclassification bias –, happens when the information gathered is not accurate, or incomplete, leading to the misclassification of the participants in relation to the exposure or outcomes of the study (Hammoudeh et al., 2018; Vandenbroucke et al., 2007). This type of errors might be averted or reduced by using validated standardized assessment tools (Hammoudeh et al., 2018).

There is disagreement among authors about the positioning of the confounding as a categorization of bias. Being this subchapter focused on the challenges that can occur during a cohort study, I choose to keep them together. Vandenbroucke et al., (2007), defend that confounding and bias aren't synonyms, since one results from inaccurate gathering of information, and the second presents correct relations, but those cannot be seen as a causality due to certain unreported factors, that are linked to both exposure and the results. Those factors are denominated 'confounders' or 'confounding factors', and

[4] More information can be found in section **Validity** .

usually represent a variable that affect the data, distorting or confusing it (Bovbjerg, 2020; Hammoudeh et al., 2018). An example of this confounding factors is:

- A study aimed to understand the risk factors for lung cancer, a strong association was found between the presence of a "lighter in the pocket" and "lung cancer". However, this relationship is not causal, because in fact, having a "lighter in your pocket" is related to being a "smoker" and it is being a smoker that is a risk factor for lung cancer.

In order to prevent all these systematic errors, both bias and confounders, the researchers must foresee where possible errors might appear (Bovbjerg, 2020; Vandenbroucke et al., 2007). To minimize the bias, Bovbjerg (2020) advice is to focus in using good design and measurement methods. And, even though is not possible to know the magnitude or direction of a bias, the researcher can make reasonable assumptions (Bovbjerg, 2020). Anyhow, they should be extremely cautious doing this guesses, and be aware that some of the bias will always remain (Bovbjerg, 2020). Looking upon the confounders, they can be managed by search previously all the variables that can confuse the study, and then adapt the study's methodology, and design, to assist in a proper gathering and analysis of the data (Bovbjerg, 2020; Vandenbroucke et al., 2007).

2.3. Health Literacy Cohort Study in Leiria

The idea of creating and implementing a Cohort Study, that evaluates the Health Literacy of the population, arose from the group that was working on the elaboration of the Health Strategy Plan of Leiria's county. It was recognized, in that document, the need of fostering "research on health literacy levels in the resident population of the Leiria county" (Câmara Municipal de Leiria et al., 2021), which was noticed in healthcare institutions records, and in consultation with stakeholders (D. S. F. Marques & Netto-Rocha, in press). One of these stakeholders were the public health doctors from Healthcare Facilities' Headquarters in the region of Leiria (ACES Pinhal Litoral). In 2019 the institution in question made a report which presented compelling evidence that a significant portion of the population of Leiria suffers from various medical conditions, such as mental health issues, diabetes, obesity, and circulatory system diseases, among others (ACES Pinhal Litoral, 2019). Moreover, the report highlighted that a substantial number of Leiria citizens, when faced with minor health issues, sought treatment at the Leiria Hospital Centre (CHL) instead of utilizing

primary healthcare facilities, thereby creating an excessive burden on the emergency units (Ferreira et al., 2022; D. S. F. Marques & Netto-Rocha, in press). These concerns awoke the interest of local researchers, and drove them to contemplate the feasibility of a cohort study to investigate the potential correlation between the health literacy levels and lifestyle habits of the Leiria's population (D. S. F. Marques & Netto-Rocha, in press).

From this existing connections, a multidisciplinary team was assembled to work on the preparatory phase of this cohort study, bringing together health representatives of City Hall of Leiria (CML), public health doctors from ACES Pinhal Litoral, researchers from CiTechcare, and designers from the Master in Design for Health and Wellbeing from School of Arts and Design of Caldas da Rainha (ESAD.CR) supported by Research Laboratory in Design and Arts (LIDA) (Ferreira et al., 2022; D. S. F. Marques & Netto-Rocha, in press). Being a team with different backgrounds, the transfer of knowledge from different areas was valuable to address crucial topics, such as identifying the target audience, establishing the goals and duration of the cohort study, determine the methodologies and approaches to employ when contacting the target audience, developing the brand communication strategies and decide how the study's team will be organized (D. S. F. Marques & Netto-Rocha, in press). Some of these topics were assessed in team, while others were handed over to the designers to solve (i.e., brand communication strategies, approaches when contacting the target audience etc.), being addressed further in this essay. One of the topics addressed as a team was the decision for the name LISA for the cohort study. LISA stands for "Estudo Longitudinal de Literacia em Saúde no concelho de Leiria", that means "Longitudinal Study in Health Literacy in the County of Leiria".

Cohort Study Goals

There are several goals identified in this cohort study. The main objective is to measure the health literacy levels in the target audience. In addition, it is also intended to characterize, in the same population sample, the levels of anxiety and depression, the metabolic risks, and alcohol and smoking habits. Another implicit goal is to gather enough people so the study can continue for the projected duration, without losing its internal and external validity. The idea is that this last goal can be achieved through communication strategies.

Methodology

This cohort study's methodology is considered prospective, as it aims to collect information over 10 years, with new measurements every 2 years, resulting in five waves. The data collection approach uses six previously validated forms (FINDRISC, HLS-EU-PT, FTND, HADS, and AUDIT), re-arranged in an online questionnaire, in order to assess the populations lifestyle habits and literacy levels. Despite being online, only the population that is approached by pre-selected and trained interviewers through the randomized door-to-door method will answer the questionnaire.

It is also possible to designate this study as closed since the population involved will be the same from the first wave up to the end of the study. This highlights the value of identifying the target group and of having a large sample that can be representative of the whole population. In this case, the multidisciplinary team opted for the adult population living in the county of Leiria, given that some of the information previously collected mentioned them. Although, the choice entails some requirements such as being 18 years old or older, having fiscal residence in one of the eighteen parishes of the county, and knowing how to communicate and understand the Portuguese language. Regarding the amount of people and counting with the possible loss to follow-up of 75%, the cohort study needs to collect data from 4003 individuals [Table 2.2]. This number (4003 individuals) is achieved by adding 75% of the population sample, corresponding to 858 male and 858 females, to the 100% of the population sample. This way if the cohort study loses 75% of the 4003 individuals, it will still represent the general population of Leiria's, maintaining the cohort studies' external validity.

Table 2.2 The number of individuals needed to have a representative sample of the population[5].

	Data		Sample Size		> 75% Dropout	
	Male	Female	Male	Female	Male	Female
18 to 29	9 367	9 165	380	380	665	665
30 to 64	30 295	32 625	383	383	670	670
+ or > 65	9 632	12 404	380	381	665	667
Total	49 294	54 194	1 143	1 144	2 001	2 002

[5] Numbers on Leiria's population according to INE (National Statistics Institute) in 2011. More detailed information on **m. Distribution of Leiria's population** .

Organization of Study's Team

Looking at the previous topics, it is important not only to organize the study, but to organise the team leading it. In meetings with the multidisciplinary team, was decided that this organization should rely on a hierarchy, at least when in contact with the audience (D. S. F. Marques & Netto-Rocha, in press). Four main figures were presented to make this contact: the Project Coordinator, the Supervisor of the Study, the Team Coach, and the Interviewers [Figure 2.3].

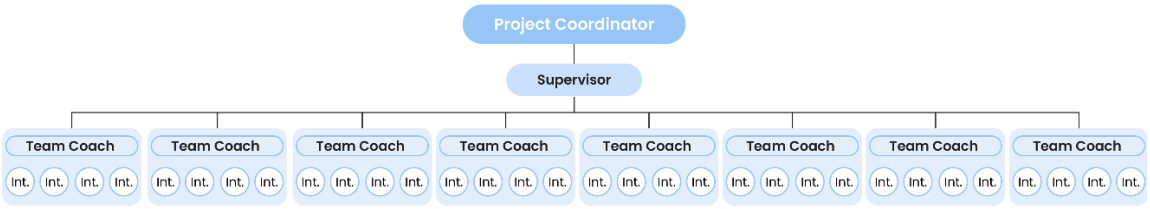


Figure 2.3 Team Organization of LISA cohort study, when contacting with the population of Leiria.

For the best use of time and funds eight teams would be needed, each with one team coach and four interviewers. In this way it is possible for each team to use only one car for transportation, and place two interviewers in each house during the interviews with the population. Having eight teams, it is possible to cover more field at once, decreasing the time needed to gather the amount of people needed for the study.

Another important part of the organization of the team is deciding what are the responsibilities and roles of each one of these figures, being that an additional task for the designers[6].

Challenges and Difficulties

The LISA cohort study faces the same challenges as all the other cohort studies: the loss to follow-up, the need for validity, the possibility of bias, etc.[7]. One of the biggest challenges of working in the preparatory phase of a cohort study is the lack of information about what to do to prevent or decrease the likelihood of these issues happening.

There are some guidelines on how to organise and analyse the results of a study of this nature, but there is no data on the preliminary phase. Although, as a designer one of my

[6] More information about these tasks can be found on chapter **5. Design Process** .
[7] More information can be found in sub-chapter **2.2 Challenges** .

tasks was to identify and solve them (further in this document will be a list of challenges identified).

A difficulty encountered was working within a multidisciplinary team. At the beginning, there were some assumptions and prejudices that people brought that hindered communication between the parties. In this case, as designers for health and well-being we faced the preconceived idea that a designer creates logos and handles the communication. And even though communication was something that needed to be addressed in this study, that was not our only role. Also connected with communication, there was the difficulty of getting enough funding and the idea that communication only needs to be done once.[8]

[8] Additional information about these difficulties will be presented in the chapter **7. Final Considerations** .

3. Design in Health

Design is a process of mutation carried out in a creative and innovative way, to achieve an intended solution (Aakhus, 2007). It can also be described as a project, a program, an invention, a form of translation, communication, etc. since it uses the application of knowledge to produce new insights (Frascara, 2004). Even though the definitions use the word design differently – in the first it is considered a "verb" and in the second as a "noun" –, both are correct(Khan & Matthews, 2019). This happens because there is no universal definition that can encompass everything a designer can do (Khan & Matthews, 2019).

The lack of consensus and the multitude of design specializations are some of the reasons why the common population fails to grasp and perceive what design is (Khan & Matthews, 2019). Even though it can be found in many ways, from the moment they wake up until they go to sleep, the majority of design forms are simply unnoticed, since it blends with the "visual culture of everyday life" (Barnard, 2005; Khan & Matthews, 2019). This gap in knowledge among the population may also be caused by designers themselves, who find it difficult to explain the value of what they do to people outside their work environment, due to the many meanings assigned to the word(Khan & Matthews, 2019). Throughout this chapter, and to counteract the actions of these designers, I will explain the versatility of design and its value, thus contributing to a better understanding of the role that a designer can play in diverse fields, namely in health.

3.1. Design Versatility

Since design is so versatile and dynamic, the designer can play multiple roles in multiple places, depending on the product, experience, or service they create (Ambrose & Harris, 2009; Khan & Matthews, 2019). Some of these roles have different denominations allied to their particular expertise, such as Product Designer, Interior Designer, Industrial Designer, Graphic Designer, Service Designer, User-Experience Designer, User-Interface Designer, etc.

According to Ambrose & Harris (2009) can be hard to explain these varieties of work since designers "work in varied environments and may rarely, or never, engage in some aspects of the practice". While the author is focused on explaining graphic designers' procedures,

from my perspective this can be applied to most types of designers. Meaning that despite specializing in one field designers may not benefit from it to its full extent, and it is also possible that they will move on to other disciplines or other types of design to complement their work (Simeone et al., 2018), or to simply allow better communication between interested parties (Ambrose & Harris, 2009). Therefore, understanding communication, the way it is connected to design and its strategies is an essential step towards the comprehension of this project and all the developed work.

Design and Communication

> "Design is a way to understand communication and an approach for investigating the social world from the standpoint of communication." (Aakhus, 2007, p. 112)

As previously mentioned, design can be described as a form of communication, and there even is a type of design entitled Communication Design. This design field is sometimes mistaken with others (i.e. Graphic Design, Information Design, Graphic Communication, etc.), since there are many specific ways of communicating (Ambrose & Harris, 2009), the barriers can be easily breached, intertwining design types. Frascara (2004) states that design should be more than just aesthetics and visuals that attract attention, it needs to use some tactics that support communication in order to produce the awaited response from a specific audience. This enlightens us that not all design creations are conceived with the intention of communicating (i.e., a designer creates a poster as a test version and doesn't share it).

Communication is present in all the social spheres (i.e. organizations, management, services, etc.)(Coancă, 2018), and since in this project the designer is working within a multidisciplinary team, is important to have knowledge and understand corporate communication terms [Figure 3.1] (Steyn, 2000). The first is **Internal Communication**, which is related to the communication within teams or organisations, in which everyone has tasks to perform and objectives to achieve (Chiu, 2002). On the other side is the **External Communication** that is destined to the specific external groups, that can either be the audience of the organization or possible partners (Coancă, 2018; Hesselink et al., 2007).

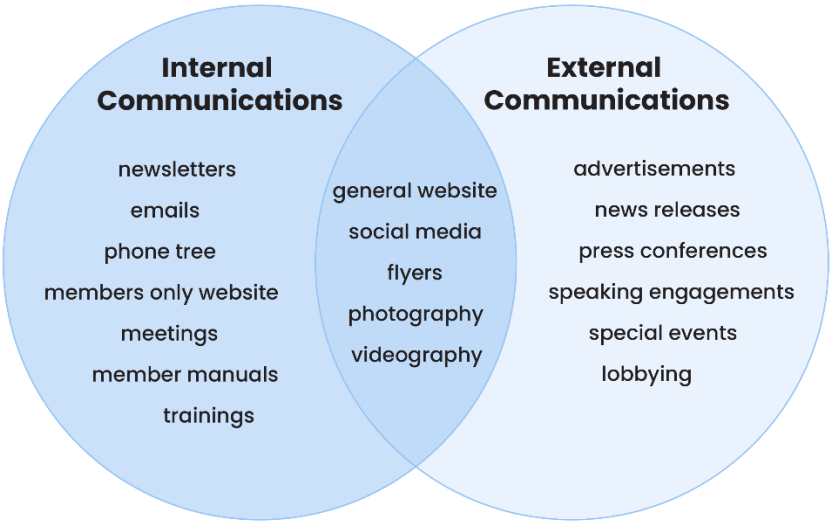


Figure 3.1 Examples of communication materials used in internal and external communications. Original graphic based on Coancă (2018) and Davis (2012).

Being communication so generic, the terms of corporate communication aren't the only ones that need explaining. In design, the knowledge of terms related to the communication stages and processes becomes crucial in order to comprehend if communication occurs in design [Figure 3.2]. Those are (Frascara, 2004):

- **Source** – wants to send a specific message.
- **Designer** – translates the message into a code.
- **Medium** – space that connects the source with the audience.
- **Content** – information the source wants to send.
- **Code** – group of signs with meaning for the audience (i.e., alphabet).
- **Form and Style** – the approach and area where the designer imprints the content.
- **Context** – circumstances that allow the message to be understood by the audience.
- **Audience** – receiver of the message.
- **Feedback** – audience response to the message received.

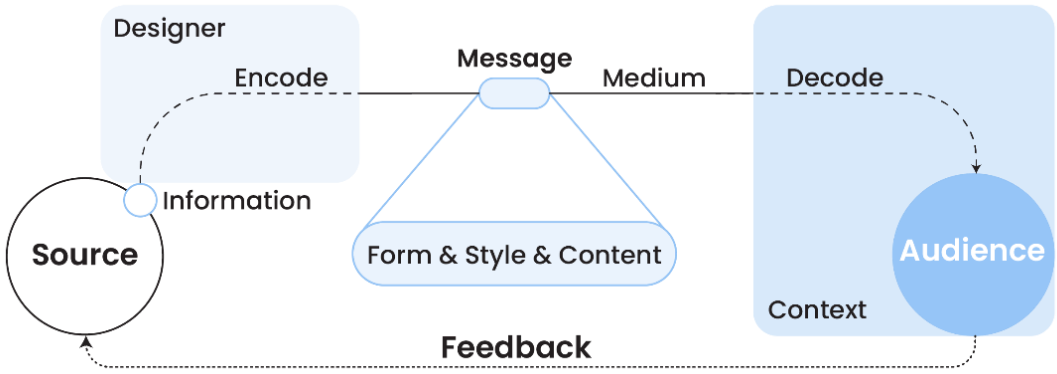


Figure 3.2 Communication Design Processes and Stages. Original infographic based on Frascara (2004) description of communication design.

While focusing on these key structures that support communication, it is crucial for the designer to reflect on the content to be passed on, which is the information. With this, another form of design surfaces, the 'Information Design'. Ambrose & Harris (2009, p. 118) state that this type of design "encompasses design strategies that are geared to the dissemination of precise information for a particular end". Then, the designer's job is to make "information understandable, usable, interesting, and if possible, pleasing" (Frascara, 2004), in order to communicate.

To ensure the information is well received it is important that the designer is aware of the 'interpretation stage'. The interpretation may be diverse from one individual to another, or specific to a group of the audience, and can neither be detached nor discarded, belonging to their cultural, perceptual, emotional, and cognitive processes (Barnard, 2005; Frascara, 2004; Norman, 2013). Don Norman (2013, p. 47) describes these processes by referring to the brain's way of functioning, which is "structured to act upon the world, and every action carries with it expectations, and these expectations drive emotions". The reaction, or feedback, from the audience is the aim of the communication, since "it is a negotiation, not sending and receiving" (Barnard, 2005). If the designer understands the audience's context, culture, beliefs, and values, it will enable communication to take place without major conflicts (Barnard, 2005).

From a designer's perspective, Aakhus (2007) states that problems found in communication are related to the gap between what was agreed that communication should be and what it presumably is. This means that what is expected of communication or design might not happen (i.e. due to the used medium characteristics – scale and

exposure time) (Ambrose & Harris, 2009). To aid with these issues, Frascara (2004) defined three concepts:

- **Information –** as mentioned before, it is precious for communication since it is related to the level of novelty the message possesses (Frascara, 2004).
- **Redundancy** – has the functions of insisting (repeating the message until it's memorized), and clarifying (using the same information in different media to be understood by a large number of people) (Frascara, 2004).
- **Noise** – a distraction that prevents the audience from receiving or understanding clearly the information (Frascara, 2004).

Usually, the word noise is connected with audio devices, but in design, it occurs on a visual, semantic, performance, or organizational level (Chiu, 2002; Frascara, 2004). Frascara (2004) explains that on the visual and semantic level diverse aspects may cause noise, such as the presence of the designer's style, the use of irrelevant information, and the use of low-quality devices, among others. On the organizational level, the existence of a simplified hierarchy (horizontal, vertical, or diagonal) facilitates the resolution of problems by enabling better access to information by any interested party (Ambrose & Harris, 2009; Chiu, 2002). By investing in a structured form of communication, the teams and organizations are investing in the resolution of problems through a performance level enabling the rapid detection of faults, which reduces the time and money spent on the intervention and invention of the process, in case it needs to be rethought (Aakhus, 2007; Hesselink et al., 2007). In addition and in order to prevent future problems in communication and design, whether internal or external (Griffin, 2015), Steyn (2000) advises on defining communication strategies. These strategies will help align communication and design with project goals by translating ideas into achievable steps, facilitating the organisation of the project, and creating a relationship with the parties interested in it (Griffin, 2015; Steyn, 2000).

3.2. Strategies in Health Environments

Steyn(2000) informs that there is no consensus, among authors, about the definition of strategy, but from her perspective, a strategy can be seen as an approach, a system, or a design. It is seen as the main determinant of whether an organization succeeds or fails to achieve its mission(Steyn, 2000). Anyway, this form of design is not tactical, contrary to what many may think, since it does not mention details on how the communication should

be done (Schiavo, 2007). Schiavo (2007) clarifies that strategies are conceptual explanations of actions, to be taken by designers, in order to achieve communication goals. This highlights the connection and dependency that both strategies and communication goals have, as well as their links to the other phases in between, particularly in regard to health environments (Schiavo, 2007; Steyn, 2000).

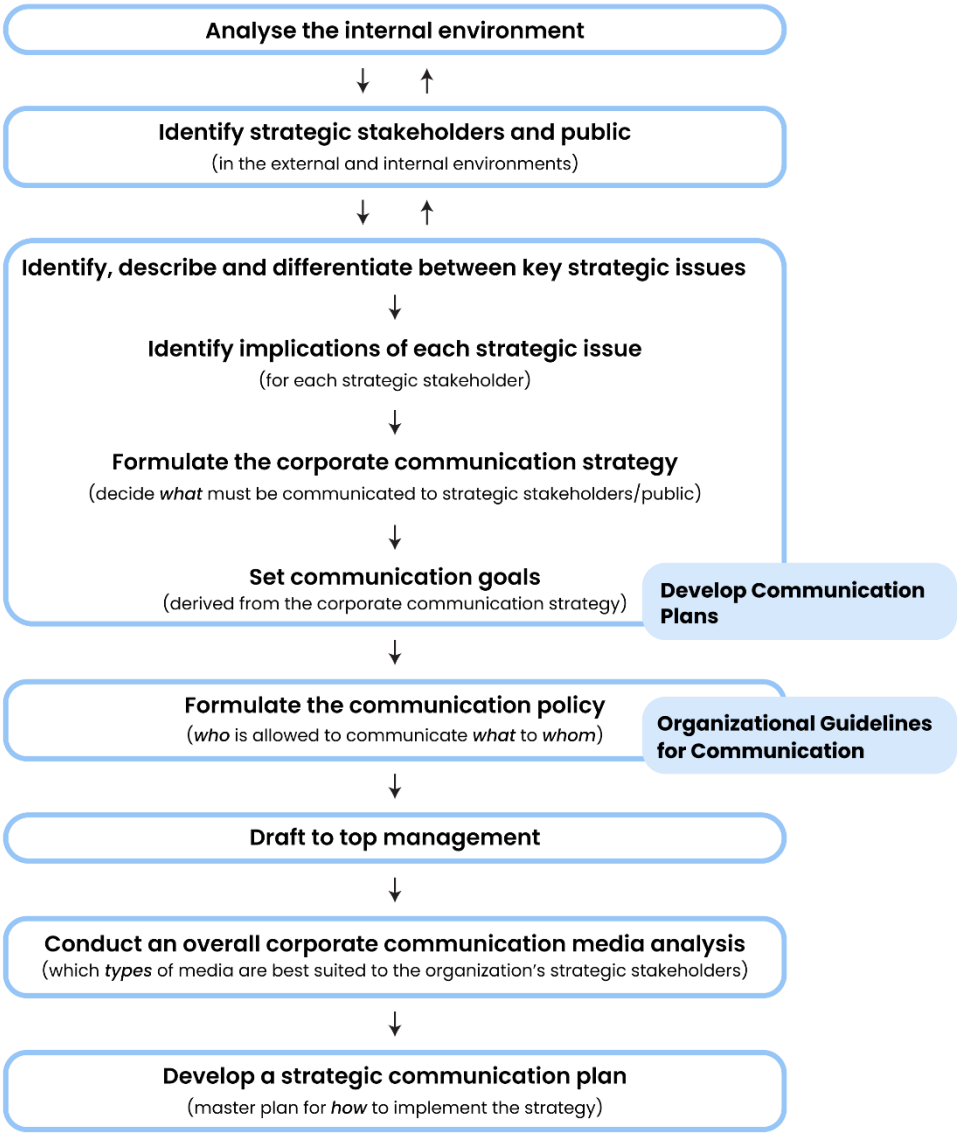


Figure 3.3 Suggested model to aid in the development of communication strategies. Adapted from Steyn (2000, p. 30).

In the health environments, is possible to find different types of planning, strategies, and models, depending on the outcome that is envisioned (Griffin, 2015). It is essential to have in mind that these strategies should always be guided by theory or empirical evidence balancing the advantages and disadvantages that may occur, especially in health (Hawkins

et al., 2008). Steyn (2000) suggests a model that may incorporate each one of the planned and supported activities into its phases [Figure 3.3]. This way, the last phase - the developed strategic communication plan - will assemble information on the communication programmes, communication campaigns and communication plans (Steyn, 2000). This model can be used in different environments - from corporate to the health sector – by making a few adjustments and providing assistance in health communication to create a safe and well-functioning environment (Griffin, 2015).

Health Communication

> "We position communication in terms of design and argue and point out how it can realize its potential for contributing to the practice and theory of organizations and health communication."(Aakhus & Harrison, 2015, p. 2)

Health communication according to Ishikawa & Kiuchi (2010, p. 1) "consists of interpersonal or mass communication activities focused on improving the health of individuals and populations". **Interpersonal communication** is described as a form of communication where someone teaches or gives advice, usually is seen as a presentation, a course, a workshop, a lecture, a discussion, etc. (Schiavo, 2007). **Mass communication** is done through media channels, being those printed or digital, and can be seen as editorials, articles, online seminars, documentaries on television, illustration, etc. (Schiavo, 2007). Even though health communication is commonly seen in the form of disease prevention or health promotion campaigns (because of mass communication), it can also occur in a conversation (i.e. between patient and provider)(Ishikawa & Kiuchi, 2010). Figure 3.4 illustrates the environments where health communication can occur:

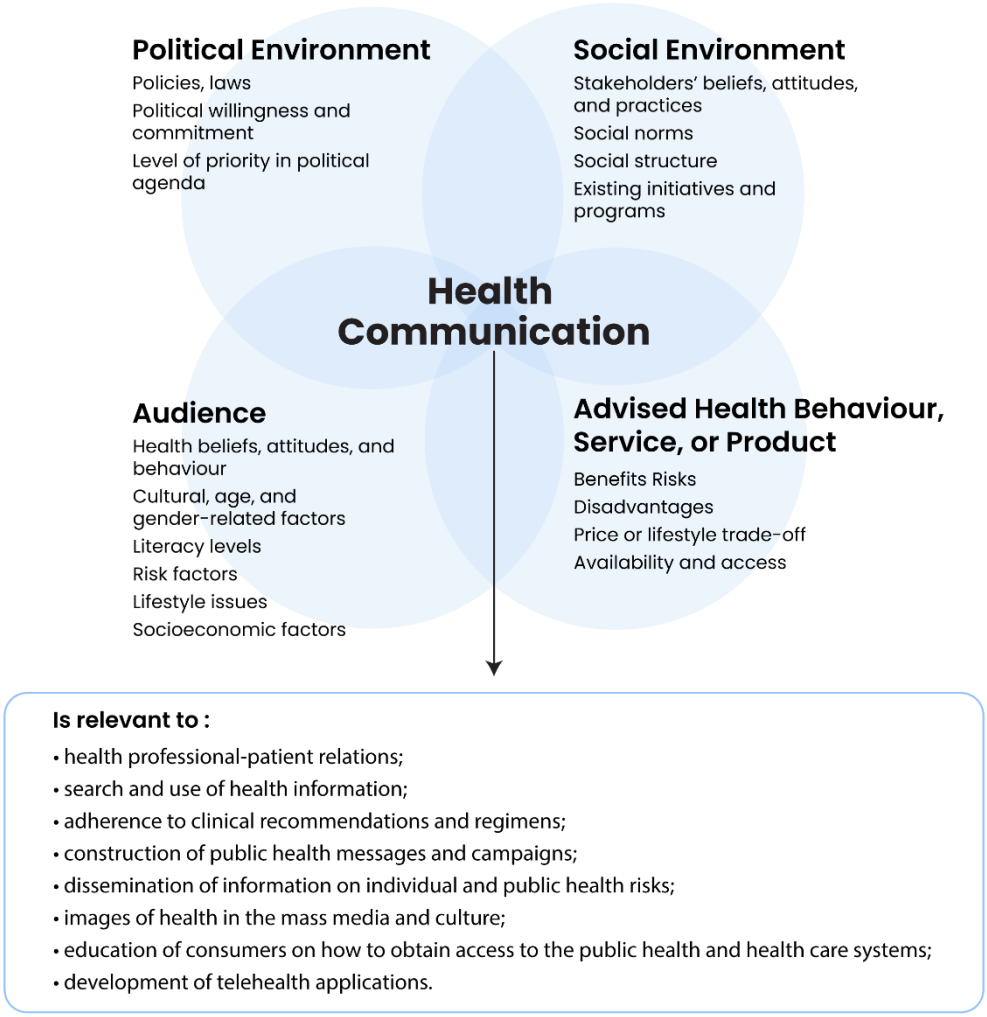


Figure 3.4 Health communication, its relevance, and connection to different environments. Figure adapted from Schiavo (2007) and completed with text from Ishikawa (2010).

The figure above shows the relevance that health communication can have in different environments, in which we can include a cohort study. Besides these, one of its possible and intended contributions is reducing and eliminating health disparities (Schiavo, 2007). For that to happen is essential to look at the **human factors** – factors related to how the individual interacts with and within the environment, and the causes that influence those interactions, or behaviours (Griffin, 2015). There are multiple human factors, but in this case, the focus will particularly be on **health literacy** (Jensen, 2012).

Health literacy according to the World Health Organization (n.d., para. 6) is "the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand and use information in ways which promote and maintain good health". This understanding and application of information may have an impact on the individuals'

behaviours and their health outcomes since it empowers them with the knowledge to have the capacity for decision-making (Ishikawa & Kiuchi, 2010). If individuals can find the health information needed and use their knowledge to understand it, they are considered functionally health literate (Jensen, 2012). If instead, the individuals do not have a priori knowledge, that is if they are not highly literate, it is very likely that their health literacy levels are also low (Ishikawa & Kiuchi, 2010).

The connection between health literacy and health communication and its values is observed when Jensen (2012) points out that "addressing [the health literacy] problem is a major health priority and one that seems to be situated within the health communication domain". This means that health literacy, more specifically, low levels of health literacy is a problem that can be tackled with the help of communication, but also that the designer, or communicator, sending the message needs to be attentive to the levels of literacy of its audience. The resolution of this health literacy problem is one of the main goals of health communication (Ishikawa & Kiuchi, 2010).

Table 3.1 Comparison of strategies of health communication in low health literacy and functional health literacy individuals. Original table based on the work of Jensen (2012).

Strategies	Low Health Literacy	Functional Health Literacy
Lower Reading Level	Lowering the reading level will aid in the comprehension of the information	Understand the information without lowering the reading level
Foundational Knowledge	Information needs to be linear to allow the understanding of messages	Can understand information implicit in messages
Repetition and Time	May need to pause or repeat content, spending more time to comprehend	May comprehend the message in the first pass
Terminology Variation	Can comprehend the message faster if standard language is used	Can understand the message even if there's a variation in terminology
Visual Communication	Perception to visuals might be higher compared with text	Perception to visuals might be the same compared with text
Automated Communication	Need for an infrastructure that allows more time to process the information	No evidence of complications with automated communication
Concerns	Less likely to concern about health	Critical thinking about health care

Table 3.1 shows that is crucial to consider and adopt the form of health communication materials to the health literacy level of the audience when designing health messages (Jensen, 2012). It also shows that increasing time and assistance may improve health outcomes - i.e. having a book that allows the low literate audience to access information repeatedly, from their home might allow critical thinking about health to be developed (Jensen, 2012). O'Sullivan et al., (2003) agrees with this need to adapt materials, stating that "literacy, language, and other considerations may indicate the need to develop

tailored materials for different groups within an audience, even if the basic message and desired behaviour change are similar". The last sentence invokes, even if implicitly, the ability of health literacy to predict health-related behaviours and outcomes, that might aid in the reduction of health disparities (Jensen, 2012).

Linked to health communication and health literacy is the term **health message design.** It is an audience-centred process, where the messages are designed to address audience needs and circumstances (Maibach & Parrott, 1995). As the term implies it can be used to develop materials to communicate related to the health environment (i.e., campaigns, books, flyers). It can either be created for individuals that demonstrate a low literacy level or for teaching and empowering healthcare providers to communicate better with that target audience (Ishikawa & Kiuchi, 2010; Jensen, 2012). In his chapter, Jensen (2012) highlights "three courses of action for those designing health messages: lowering the reading level, facilitating learning hierarchies, and allowing for repetition of content" [Table 3.1], while stating that it is important to be cautious about the over-simplification of messages and the adoption of strategies that do not have solid evidence of their benefits. And speaking about strategies, it is important to understand why health message designers often use persuasive strategies, such as (Maibach & Parrott, 1995):

- **Fear appeal –** a message invokes fear when suggests the audience might be vulnerable to a threat, while at the same time, offering easy and effective solutions. This strategy can promote better health as well as change health behaviours.
- **Positive affect** – the message uses emotional benefits in form of comparison or testimonials, becoming a good attention-getting device. This strategy can influence social behaviour and cognitive processes, by giving the audience a sense of control and reducing their fear or anxiety.

These strategies and their efficiency depend on the audience and on the psychological functioning of each individual (O'Keefe, 2012). However, in general, loss-framed appeals, such as fear appeals and negative events, tend to be more persuasive and evoke stronger and faster reactions than gain-framed appeals, like the positive affect (O'Keefe, 2012). The author O'Keefe (2012, p. 5) also states that "negative information is generally more powerful than positive information". Although it's important to remember that a message is composed of more than just content, it has features (colour, text, language, etc.) that contribute to the effects the health message can have on an individual (Yzer, 2012). It is also essential to know the communication target, for the strategy to be applied correctly.

If the purpose is to inform the audience, a persuasive strategy will not be effective, since "the message should contain facts about the problem, causes and solutions", not appealing to emotions (Hesselink et al., 2007).

Besides this, designers of health messages must acknowledge how, when and why health messages might motivate people to change their behaviours, and should reflect on innovative ways to introduce information, especially when it may contain sensitive data (Maibach & Parrott, 1995). Additionally, Maibach & Parrott (1995) gathered a list of strategies that will trigger interest and motivation for the health message, even if the individual does not have a cause for concern (i.e. a relative or colleague diagnosed with a disease). Those strategies are related to the display of "content and linguistic variables that motivate cognitive effort:

1. Use novel messages, settings, and media to present health messages.
2. Consider discrepant and unexpected messages, settings, and media to present traditional health messages.
3. Instruct the audience to pay attention to the message.
4. Construct health messages in a denotatively specific manner.
5. Choose spatially immediate demonstratives.
6. Use temporally immediate speech.
7. Avoid the use of qualifiers in relation to establishing a need to change behaviours; instead, identify the probabilities associated with specific outcomes of certain behaviours." (Maibach & Parrott, 1995)

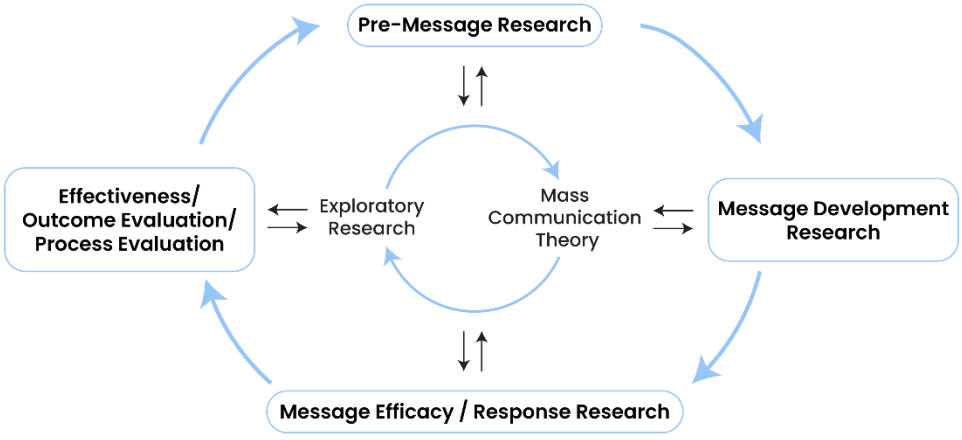


Figure 3.5 Process of designing health messages (theory based). Adapted from Maibach & Parrott (1995, p. 182).

There are a lot of theories and strategies regarding health environments and their communication, and public health has limited funds and time which leads to the use of

intuitive approaches rather than theoretical ones (Frascara, 2004; Maibach & Parrott, 1995). For this Maibach & Parrott (1995) consider the idea of using a framework to clear up the confusion between strategies, being it based on the most effective and persuasive theories and only on what should be done by designers, without the need to explain human behaviours and factors[9] [Figure 3.5]. But it might be difficult to achieve since health communication and human factors, such as health literacy, are intertwined, and modern society - including the LISA Cohort Study - is concerned about the capacity of the population to manage their health and change their behaviours to improve health environments (Ishikawa & Kiuchi, 2010).

3.3. Designers in Health Cohort Studies

Nowadays, the concept of design is presented as an innovative and significant movement to address social problems, and to address health issues[10] (Aakhus & Harrison, 2015). In their article, Aakhus & Harrison (2015) talk about the designers' potential role in health, especially connected to design and communication research. The same authors also inform that "health practice is not simply located in any one message, campaign, information system, hospital, clinical practice, medical technology, or doctor-patient interaction"(Aakhus & Harrison, 2015, p. 4). This leads one to think of the variety of places where design can intervene in health, other than communication.

Frascara (2004, p. 4) defends that a designer "must have an ability to work in interdisciplinary teams and to establish good interpersonal relations". This means that designers must know how to talk with other specialists, regardless of their field (Frascara, 2004). This requirement to obtain knowledge and team integration skills is found especially in the health sector, where the designer may encounter professionals of healthcare - doctors, nurses, pharmacists, psychologists, etc. - or individuals whose profession may not be immediately related to health – managers, sociologists, other designers, etc. (Frascara, 2004). Working close with diverse specialists might aid the designer to find their role in the health field, particularly in health cohort studies. Even if, it is difficult to find evidence supporting the idea of designers working in a cohort study.

[9] The authors inform the necessity of comprehensive guidelines (one of the goals of this dissertation).
[10] More information about this in the section **Health Communication** .

4. Designers' role in LISA

The Designer for Health and Well-being specialization is quite recent in Portugal, and despite the understanding of the designer's skills, it has not been easy to identify their role in society. This difficulty stems from prejudices and widespread ideas in the Portuguese population about what a designer should do. As outlined in the previous chapter, the design-health connection is, in its majority, associated with the communication. This was one of the premises the designers found when enrolled in the LISA Cohort Study.

The multidisciplinary team of the LISA Cohort Study had already started the ideation phase when the call for two master's students from the course of Design for Health and Well-being was made. The team's idea of bringing in designers was so that they could assist in the process of creating a brand for the study and its communication elements (Ferreira et al., 2022). Since there is no requirement for communication knowledge when attending the Design for Health and Well-being master's degree, the assumptions of the team caused some friction and discomfort in the process of searching for the designers' purpose. Adding to this, the organising team suffered changes with the arrival of new representatives, some from the CHL that decided to join the study, and other as replacements of CML due to the municipality elections and the termination of the mandate. As the study was still in its early stages of development and unable to have regular face-to-face meetings with the whole team, the original schedule had to be revised. For situations such as these, Griffin emphasises that:

> "Whenever a person leaves the team, his or her replacement must become familiar with the project's history, goals, description, elements, phases, status, and so on. Without thorough documentation, valuable time and knowledge can be lost, which opens the door for poor, uneducated decisions and potentially increased costs for time overruns and error remedies"(Griffin, 2015, p. 25).

Besides being unusual to have designers at the beginning or in the preparatory phase of a project, such as in a cohort study, there is a lack of evidence on how to proceed. Rissanen

(2020) defends that applying concepts, innovations and processes from different fields can help in the creation of a more accurate, strong and easy-to-understand solution for all the interested groups. Then, in the course of numerous meetings with the LISA's team (interactions occurred as presented in Figure 4.1), it was possible to clarify the designers' skills and knowledge of design methodologies, identify the multiple ways in which designers could contribute to the preparatory phase of LISA Cohort Study and define that process (Ferreira et al., 2022; D. F. Marques & Netto-Rocha, 2022; Netto-Rocha & Marques, 2023).

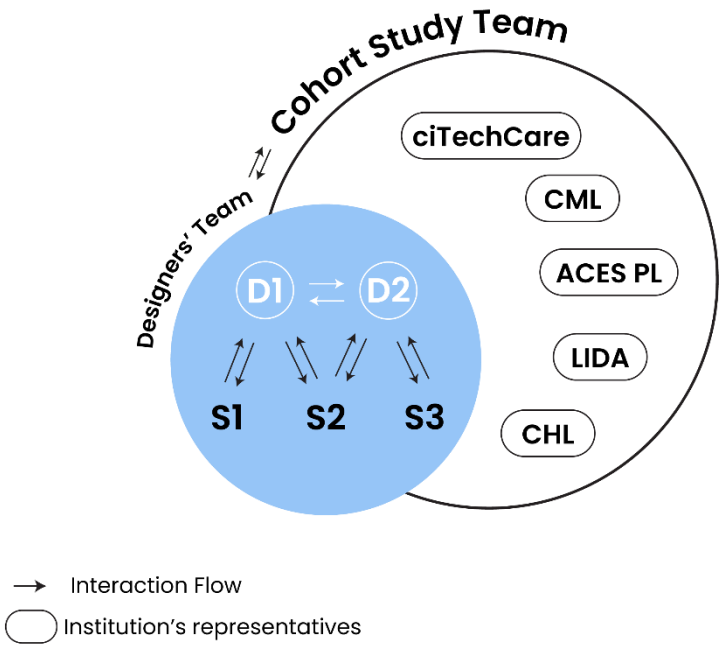


Figure 4.1 Visual explanation of how most interactions occurred within the LISA's Team, with a particular focus on the Designers' Team. "D1" and "D2" stand for the two design students, and "S1", "S2" and "S3" for the designers' dissertation supervisors. Original graphic.

4.1. Designers' Purpose

The designers' roles in LISA were to develop communication materials and processes, which would allow interactions between the population of Leiria, the staff of the cohort study and its multidisciplinary team, and to use appropriate design methodologies to both define and guide the preparatory phase. Throughout the process we realised that the objectives of the project [Figure 4.2] and of LISA cohort study were not the same[11].

[11] More information in section Cohort Study Goals .

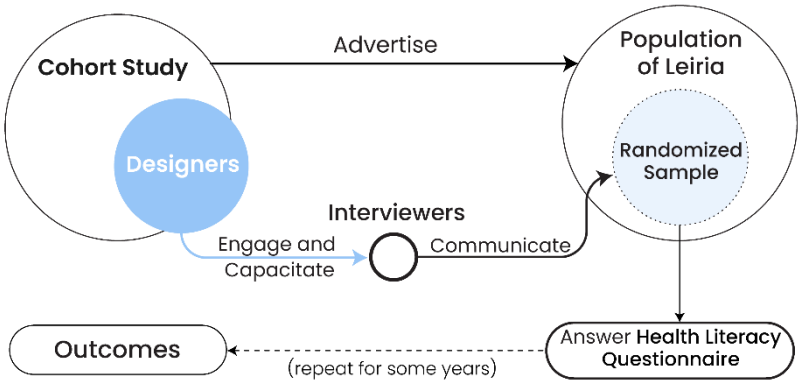


Figure 4.2 Designers' aims in the LISA cohort study process. Original graphic.

This project aims for advertising LISA, keep participants engaged and capacitate the interviewers to communicate effectively with the adult population of Leiria, who is diverse in age, gender, social backgrounds, and each have ideal and specific communication needs.

The clarification of these objectives was important as it enabled the identification of the users and stakeholders of this project. The user can be anyone from LISA Cohort Study, that will interact with the population of the municipality of Leiria, namely interviewers, team coaches, supervisors and any person belonging to the organising institutions. Even though the last group presented might be a user, at the same time is a stakeholder, since they belong to the organising institutions of the LISA cohort study. To better clarify it and following Steyn (2000, p. 17) advice, a mapping of the everyone directly involved in the study was created [Figure 4.3].

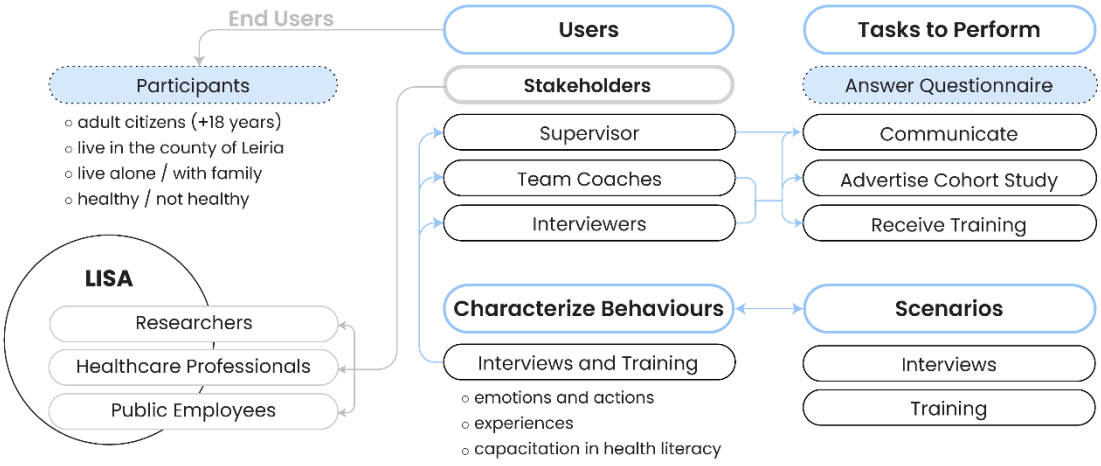


Figure 4.3 Mapping the organisation of LISA and design project, focusing on users, stakeholders, and touchpoints. Original graphic.

4.2. Design Framework

The design process was defined based on the goals that the designers were committed to achieve, but as stated earlier, the presented project was being developed by two design students and would be integrated in their master's dissertations. Therefore, it was crucial to create a process where they could cooperate, while considering the need to have distinct tasks where the designer could perform individually, in order to distinguish their work.

In this process the "design" team defined the methodologies and methods to be used, and each of the designers organized them into a design framework [Figure 4.4], that would better fit in their projects. The process was dynamic and isn't linear, since some of the methods will be used at the same time, and others will be validated by the previous ones.

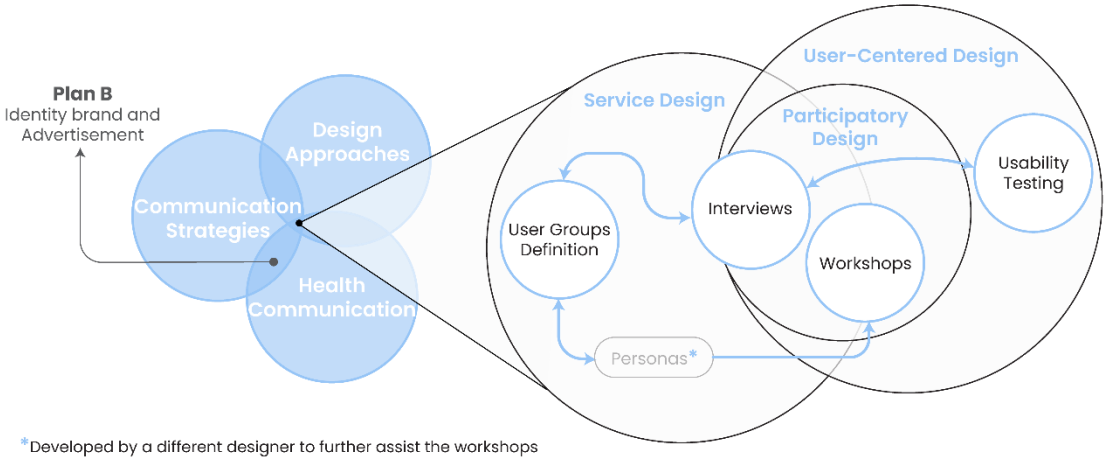


Figure 4.4 Design Framework of this master's dissertation. Original graphic.

Looking at the figure is possible to understand the connection of three major areas: Communication Strategies, Health Communication, and Design Approaches. The connection between the first two areas is evident and was already identified in previous chapters. So based on Communication Strategies and Health Communication a Plan B was conceived with the intention of helping to advertise LISA to the population of Leiria county. It proposed to develop an identity brand and communication materials and it is designated Plan B, because, as stated before, the communication was not our main purpose when joining LISA. The last major area, Design Approaches is in this framework since the methodologies of Service Design, Participatory Design and User Centered-Design

were used to obtain answers regarding the stakeholders and users' needs, behaviours, likes and choices, while involving them in the decision-making process[12][Figure 4.5].

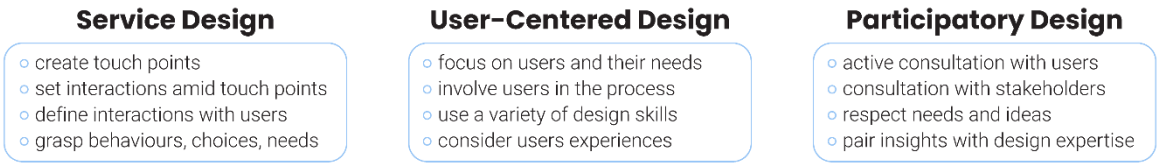


Figure 4.5 A brief overview of the characteristics of each of the methodologies. Original graphic based on the descriptions of Design Council & Technology Strategy Board: Driving Innovation (2015), Interaction Design Foundation (n.d.) and Martin & Hanington(2012).

Service Design

> "It is a human-centered, collaborative, interdisciplinary, iterative approach which uses research, prototyping, and a set of easily understood activities and visualization tools to create and orchestrate experiences that meet the needs of the business, the user, and other stakeholders" (Stickdorn et al., 2018, Chapter 2)

Service Design according to Stickdorn et al., (2018, Chapter 2) "can be explained in many ways". As a mindset is based on pragmatism, co-creation and practical skills (Stickdorn et al., 2018). At the same time it can be considered a collection of tools, or methods, that can stimulate and trigger significant conversations, and clarify implicit knowledge to generate common understanding (Stickdorn et al., 2018). It is also a multidisciplinary process, which most tools were developed by public organisations, institutions, academia etc. (Morelli et al., 2020).

Morelli et al., (2020) reports that when using service design, a designer can act on three different logical levels [Figure 4.6]: interactional, infrastructural and institutional. The service as interaction is observed according to a time and context, when in order to co-generate value, the designer facilitates the contact between the service users, other actors and the infrastructure (Morelli et al., 2020). The second case, service as infrastructure can be noticed when the value creation is in the design process and in the infrastructure (Morelli et al., 2020). Lastly the service as a systemic institution encompasses all the

[12] The information presented here is part of a school assignment developed in the course of Translation Design (part of the master's 2nd year) that accompanied the preparation of this dissertation regarding methodologies.

changes that are done in that institutional system, including innovation, culture, social conditions, etc. (Morelli et al., 2020).

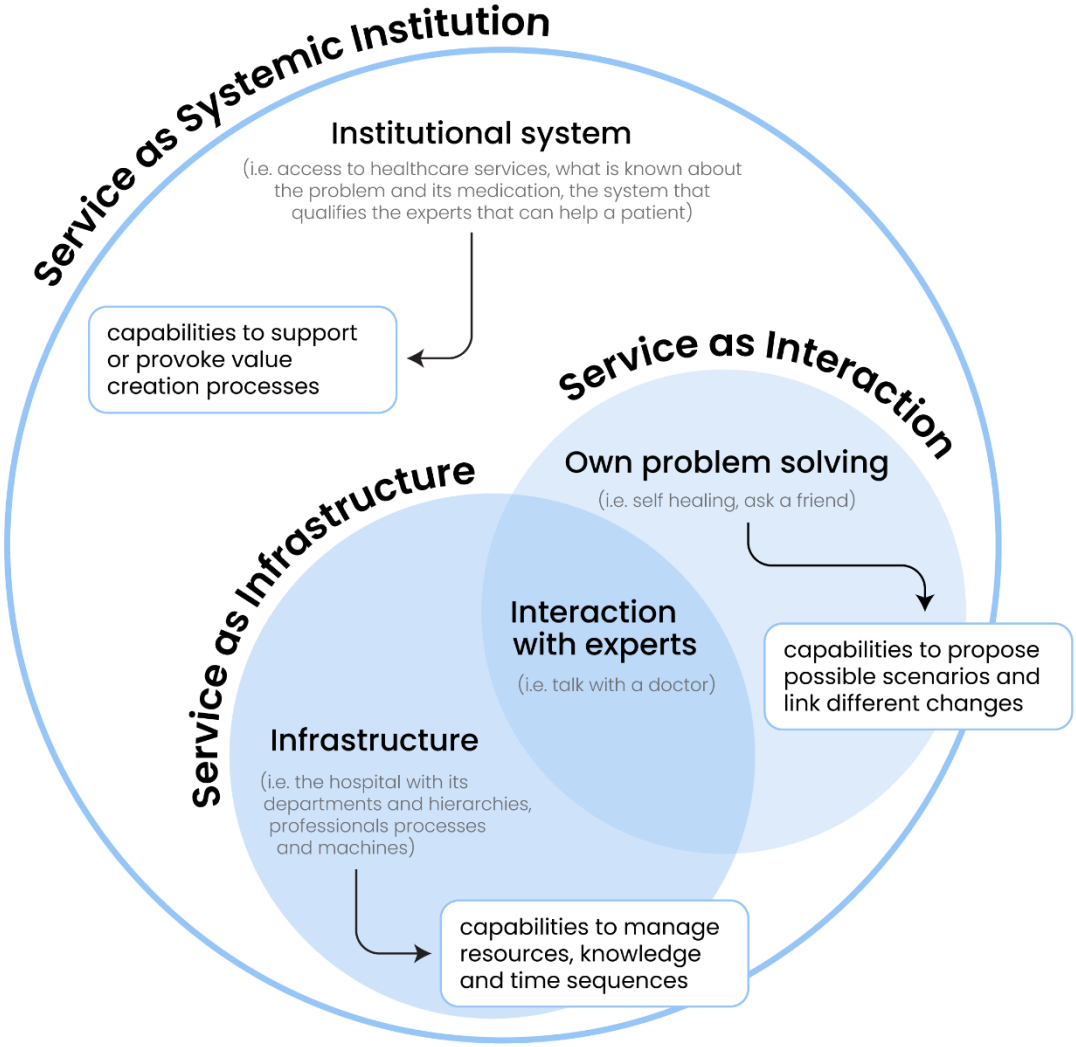


Figure 4.6 The three different logical levels and the needed capabilities. Original based on Morelli et al., (2020).

For each of these logical levels, it is necessary that the designer possesses a set of capabilities to solve the problems inherent to them. The capabilities can also enable the resolution of problems related to the expansion of service design to other disciplines, especially when there's no possibility to talk to experts from that field (Morelli et al., 2020; Yang & Sung, 2016). The **Table 4.1** shows all the capabilities a designer must have to be able to use this approach correctly:

Table 4.1 Description of designers' capabilities. Adapted from Morelli et al., (2020, p. 29).

Name of the Capability	General Description
Addressing the context	The capability to identify and respond to relationships between a solution and its context
Controlling experiential aspects	The capability to empathise with people and address experiential features of possible solutions
Modelling	The capability to simulate, visualise and experiment with possible solutions before all the information is available, using form to embody ideas and communicate values
Vision building	The capability to figure out coherent possible futures
Engaging stakeholders	The capability to initiate and facilitate participatory co-creation processes
Working across levels	The capability to work through different levels of abstraction
Building logical architecture	The capability to articulate or identify logical structures to frame problems and creative activities
Open problem solving	The capability to identify solutions across different logical domains and within uncertain and ambiguous contexts

With the access to these capabilities, the designers can support changes in diverse organizations, places and institutions (Weisser, 2021), what may include cohort studies. With all this in mind, methods from the Service Design scope such as personas, interviews, and user group definition were selected. Also, some tools as service design blueprint and green and red feedback were brough into play for the development of LISA.

User Centered-Design and Participatory Design

> "PD is more than a particular implementation of UCD."
> (Carroll, 1996, p. 289)

The methodologies User-Centered Design and Participatory Design are usually connected. Participatory Design methodology is normally understood as an approach to User Centered Design, but there are some differences that should be considered (Carroll, 1996).

User Centered Design is an approach in which the users and stakeholders' needs and expectations influence a final design (Abras et al., 2004; Sanders, 2002) – that can be either a product, service or experience. This influence is brought into the project when a designed solution is given to the users for evaluation, after being prepared with all the analysed stakeholders' needs (Abras et al., 2004). Usually, it is done so users will be satisfied with the solution(Abras et al., 2004), more frequently relying on its use.

Abras et al., (2004, p. 767) sates that teams that use User Centered Design "generally benefit from including persons from different disciplines, particularly psychologists, sociologists and anthropologists whose job it is to understand users' needs and communicate them to the technical developers in the team". This shows the importance of understanding users and their experiences. The same authors, describe that besides the advantage, it can raise difficulties related to the communication, since the 'language' of designers can have some terminologies that will need explaining[13] (Abras et al., 2004). When that occurs, designers need to be prepared to use visual materials as *mockups* (Abras et al., 2004), to facilitate the transfer of information. The **Table 4.2** elucidates the advantages and disadvantages of this methodology:

Table 4.2 Advantages and Disadvantages of User Centered Design. Adapted from Abras et al., (2004).

Advantages	Disadvantages
Products are more efficient, effective, and safe	It is more costly
Assists in managing users' expectations and levels of satisfaction with the product	It takes more time
Users develop a sense of ownership for the product	May require the involvement of additional design team members and wide range of stakeholders
Products require less redesign and integrate into the environment more quickly	May be difficult to translate some types of data into design
The collaborative process generated more creative design solutions to problems	The product may be too specific for more general use, thus not readily transferable to other clients; thus more costly

"In participatory design the users are involved in development of the products, in essence they are co-designers" (Abras et al., 2004, p. 766). When using this methodology, the design becomes a researcher that should not only listen to what the users have to say but also see what they do with the solution to understand the way they think, act and feel (Sanders, 2002). To allow the design to empathize with the user, a variety of tools and design principles can act as a guide evoking the participation of the user (Abras et al., 2004; Carroll, 1996; Sanders, 2002). If this methodology is applied to a health field it can also

[13] These difficulties raised by the authors, were also found within the LISA Cohort Study team.

require a methods with a political dimension "by seeking to re-configure the relationships of power between citizens and public services" (Donetto et al., 2015, p. 243).

The biggest difference between User Centered Design and Participatory Design is that the first can exist without the second, while the second will not work without the first. What I mean by this is that User Centered Design doesn't need to be participatory, it can be user centric by resorting to records, or other types of reports, where the users have shown their expectations, without them being part of the team (Abras et al., 2004; Carroll, 1996). On the other hand, Participatory Design is not only focused on the user, as it considers them as a partner (Abras et al., 2004). Knowing the correlation of this methodologies, methods such as interviews, workshops and usability testing were used allowing to get a sense of what users and stakeholders are looking for when developing the LISA study.

Design Approaches

As outlined previously, the methodologies Service Design, Participatory Design and User Centered Design were chosen by the design team for their potential to guide the development of the projects. Each of these methodologies encompasses certain methods and these can belong to more than one methodology due to their broadness, always depending on the way they were applied [Table 4.3]. In this project, the employed methods were usability testing, interviews, user group definitions and workshops of Service Blueprint and Red and Green Feedback (Design Council & Technology Strategy Board: Driving Innovation, 2015; Interaction Design Foundation, n.d.; Kumar, 2013; Martin & Hanington, 2012; Moeller et al., 1980; Moran, 2019; Stickdorn et al., 2018).

Table 4.3 Description of the used methods and their purpose in the LISA Cohort Study. The goals of each method are connected with their descriptions, found in different authors works (Design Council & Technology Strategy Board: Driving Innovation, 2015; Interaction Design Foundation, n.d.; Kumar, 2013; Martin & Hanington, 2012; Moeller et al., 1980; Moran, 2019; Stickdorn et al., 2018).

	Methods	Purpose in LISA	Methodologies
Initial Phase	**Usability Testing**	◦ Collecting data related to the usability of the Health Literacy Questionnaire ◦ Identify problems and opportunities to improve the questionnaire ◦ Learn about preferences and behaviours of the users	User-Centered Design
	Interviews	◦ Gather information about issues in previous cohort studies (experts) ◦ Empathize with the needs and ideas of the population (population sample) ◦ Validate the map created in the user groups definition method	Participatory Design & Service Design & User-Centered Design
	User Groups Definition	◦ Determine characteristic groups in the Leiria Adult Population ◦ Form a group to facilitate comparison within the population	Service Design
Final Phase	**Personas**	◦ Identify profiles for the three levels of hierarchy in LISA: interviewer, team coach, supervisor	Service Design
	Workshops	◦ Validate the personas developed ◦ Discovery of the ideal profile for the LISA field team ◦ Create a structure for LISA ◦ Identify challenges that can occur in LISA	Participatory Design & Service Design

5. Design Process

The design process started with the aim of gathering information about the potential issues that might occur in a cohort study and possible ways in which designers could address them. To have a broader overview we carried out a literature review. To complement it, the designers found that it was useful to talk to individuals who had been through similar experiences - i.e., experts in the field of cohort studies in Portugal – and to talk to some individuals who could represent the population of Leiria being addressed by the LISA cohort study. Besides this, it would be important to understand if the questionnaire to be used in the LISA study was understandable by any person within the population, and what would be the most appropriate way to implement it. Thus, the usability testing and interview methods were used simultaneously, accompanied by the user group definition that would allow us to perceive the type of population that the LISA cohort study might address.

In the final phase of our involvement in LISA, personas and two workshops were set up which, with all the previous collected and analysed data, allowed us to have a vision of what the cohort study really needed. Unlike the previous methods they did not occur simultaneously, but rather depended on each other, since the personas would be validated during the workshops.

Throughout the design process, and sometime between the methodologies analysis and their implementation, Plan B was taking place. This plan, which is related to communication, was developed because the study needed to be disseminated, and considered some insights coming from Leiria's population and stakeholders. It is worth mentioning that because the tasks were divided between two designers, part of plan B, namely the website was done by my colleague, while I focused on the graphic and printable elements.

Throughout this chapter I will talk about how the methods were developed, implemented, and analysed [Figure 5.1]. For a better explanation of all the communication developed and an overview of how the methods mutually supported each other I advise you to consult Constança Netto-Rocha's dissertation.

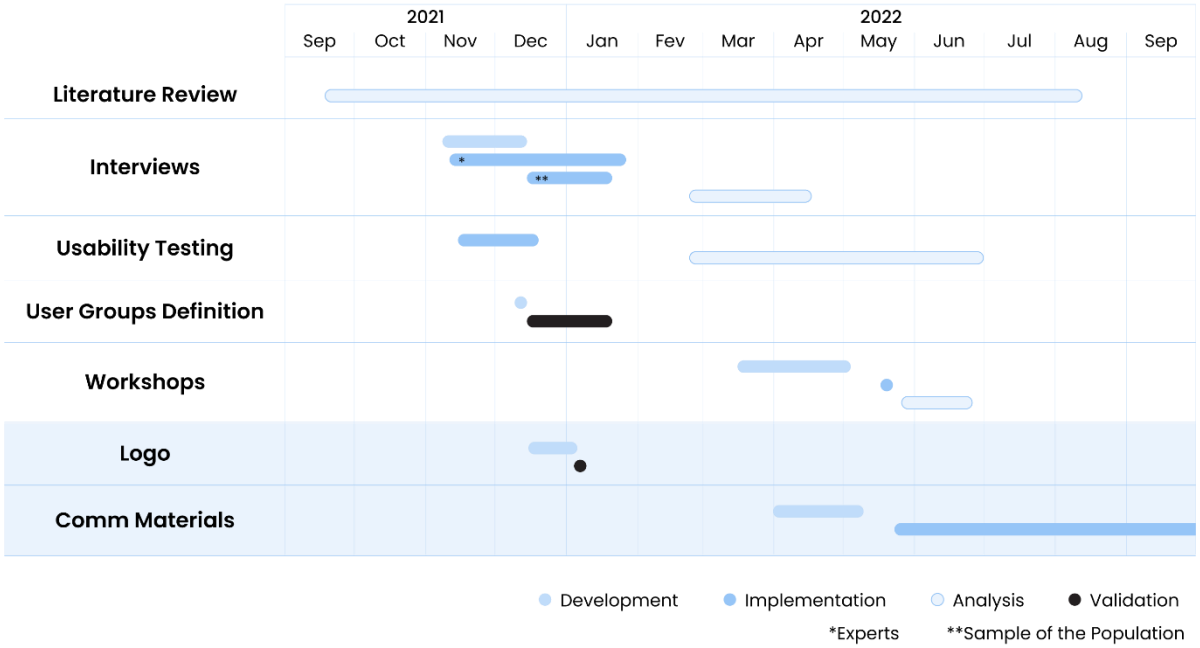


Figure 5.1 Timeline of the Design Process. The Personas method is not part of this timeline since it was developed by Constança Netto-Rocha.

5.1. Usability Testing

Usability Testing was the first method to be used, aiming to understand the usability of the health literacy questionnaire previously developed by the multidisciplinary team of the cohort study. As stated above, the questionnaire contains six surveys with scientific review and validation:

- 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 of these surveys has already been scientifically validated therefore changing the questions is unfavourable - the time and effort for a new validation would deviate from the intent and purpose of the LISA study. So, in this case, the designer started by doing usability testing to grasp how the population would react to the combination of surveys, and how they could be improved for better perception and understanding.

The selection of enough representatives of the population to do usability testing of the questionnaire, was connected with the formula of Tom Landauer "$N(1-(1-L)^n)$" that shows "N is the total number of usability problems in the design and L is the proportion of usability problems discovered while testing a single user" (Jakob Nielsen, 2000). According to Jakob Nielsen (2000) this formula comes from analysis of several studies in which the method has been used, finding that typically the value of L=31%.

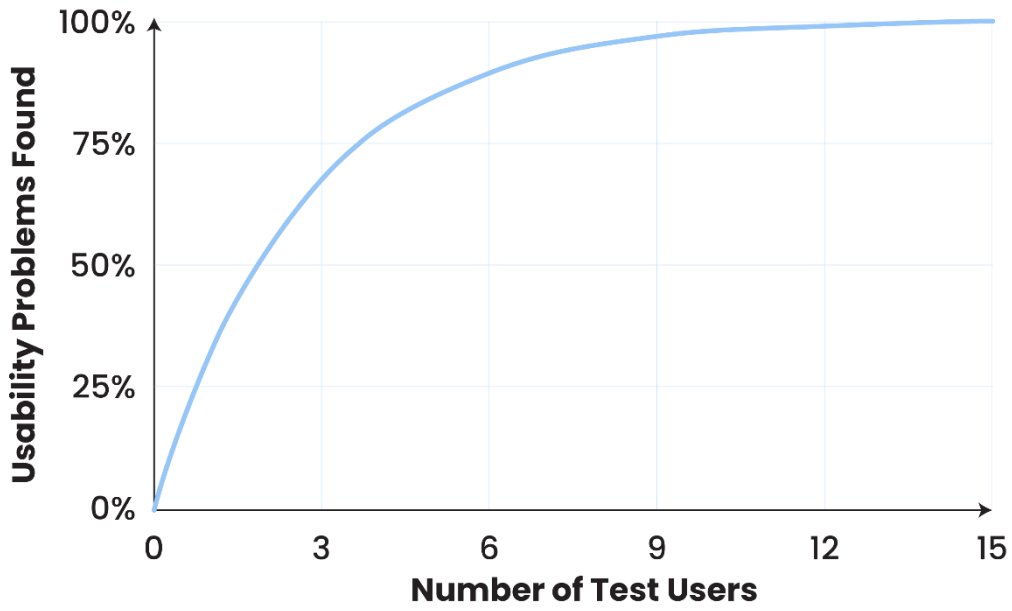


Figure 5.2 Graphic of the formula "$1-(1-L)^n$" adapted from the article of Jakob Nielsen (2000).

From this information [Figure 5.2] it was clear that with fifteen users it is possible to find all the problems of a product, in this case the questionnaire of the LISA study. Jointly with the multidisciplinary team we attempted to gather that number of people, but due to time constraints and the situation of covid-19 only seven users were recruited.

Table 5.1 Individuals who have participated in usability testing and difficulties found.

	ID & Date	Age (years)	Digital Literacy	Difficulties Found	Time (min.)
Phase 1	**User 01** **15 / 11 / 21**	47	High	◦ Misleading layout in some questions ◦ Need some additional information ◦ Similar and repetitive questions cause confusion	48
	User 02 **01 / 12 / 21**	18	Medium	◦ Certain questions are meaningless ◦ Prefer reading the questions for better understanding ◦ Replies without reading the section information	27
	User 03 **03 / 12 / 21**	67	Medium - Low	◦ Misleading layout in some questions ◦ Unclear and confusing questions ◦ Challenges in using diverse electronic devices	29
Phase 2	**INT 01** **15 / 12 / 21**	78	Low	◦ Need for assistance filling in the questionnaire ◦ Misunderstands the meaning of the questions ◦ Need some additional information	26
	INT 02 **15 / 12 / 21**	22	Medium - High	◦ Unclear and confusing questions ◦ Health skills help to understand the questionnaire ◦ Prefer reading and filling the questionnaire	20
	INT 03 **15 / 12 / 21**	55	Medium	◦ Lack of focus when answering the questionnaire ◦ Need some additional information ◦ Prefer someone to read the questionnaire	50
	INT 05 **21 / 12 / 21**	24	High	◦ Unclear and confusing questions ◦ Many answers depend on previous experience ◦ Prefer someone to read the questionnaire	20

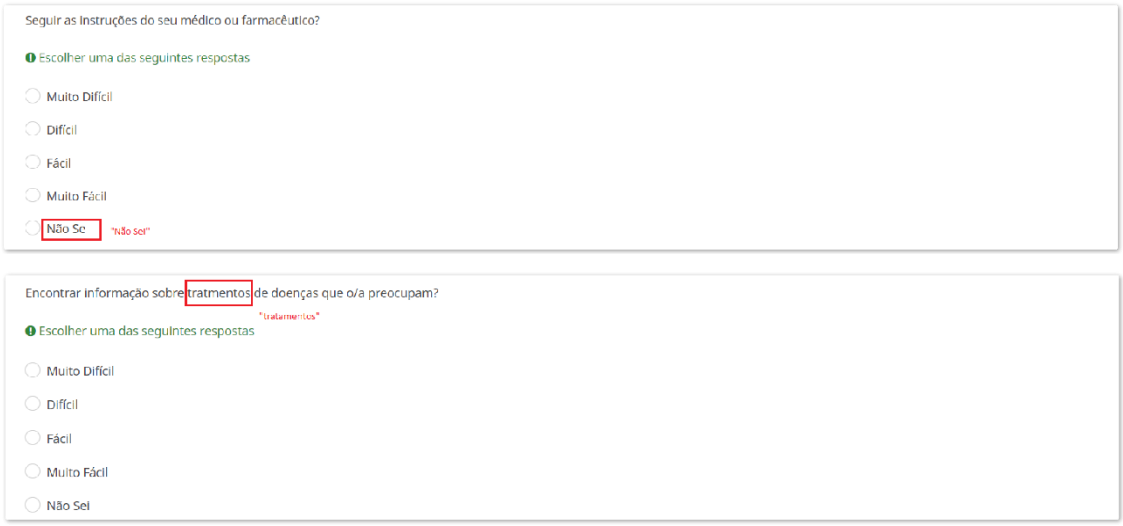
In the Table 5.1, there are three people who tested the primitive questionnaire, before any changes were made by the designers, both in format and content. They were not residents of the municipality of Leiria, but allowed a better understanding of what should be changed before testing it in the interviews with the population sample.

The multidisciplinary team made initial adjustments to the LISA questionnaire, so it could be tested during some of the interviews with the population sample [Table 5.1]. Since the questionnaire was extensive and time consuming, some of the people interviewed did not take the test. By doing this it was possible to counter the constant slippage in the schedule, which had already occurred due to changes of representatives in the multidisciplinary team.

During the second phase of usability testing, the goal was to identify the format that the interviewers of the LISA study should adopt to receive a better response from the population to the questionnaire. Over the course of the sessions, it became clear that depending on the age and digital literacy level, the ideal format would change. As a result, in cooperation with the multidisciplinary team, it was decided that the interviewer would ask the questions and note down the answers, so that the methodology would be the same for all LISA participants, standardising the process.

Analysis

From the initial phase of this project until the end, changes were always made by the multidisciplinary team, with and without the consent of the designers. The designers did not have access to the platform where the questionnaire was created, so they only communicated the most significant changes to the team verbally or by email. Below are some of the changes requested by the designers:



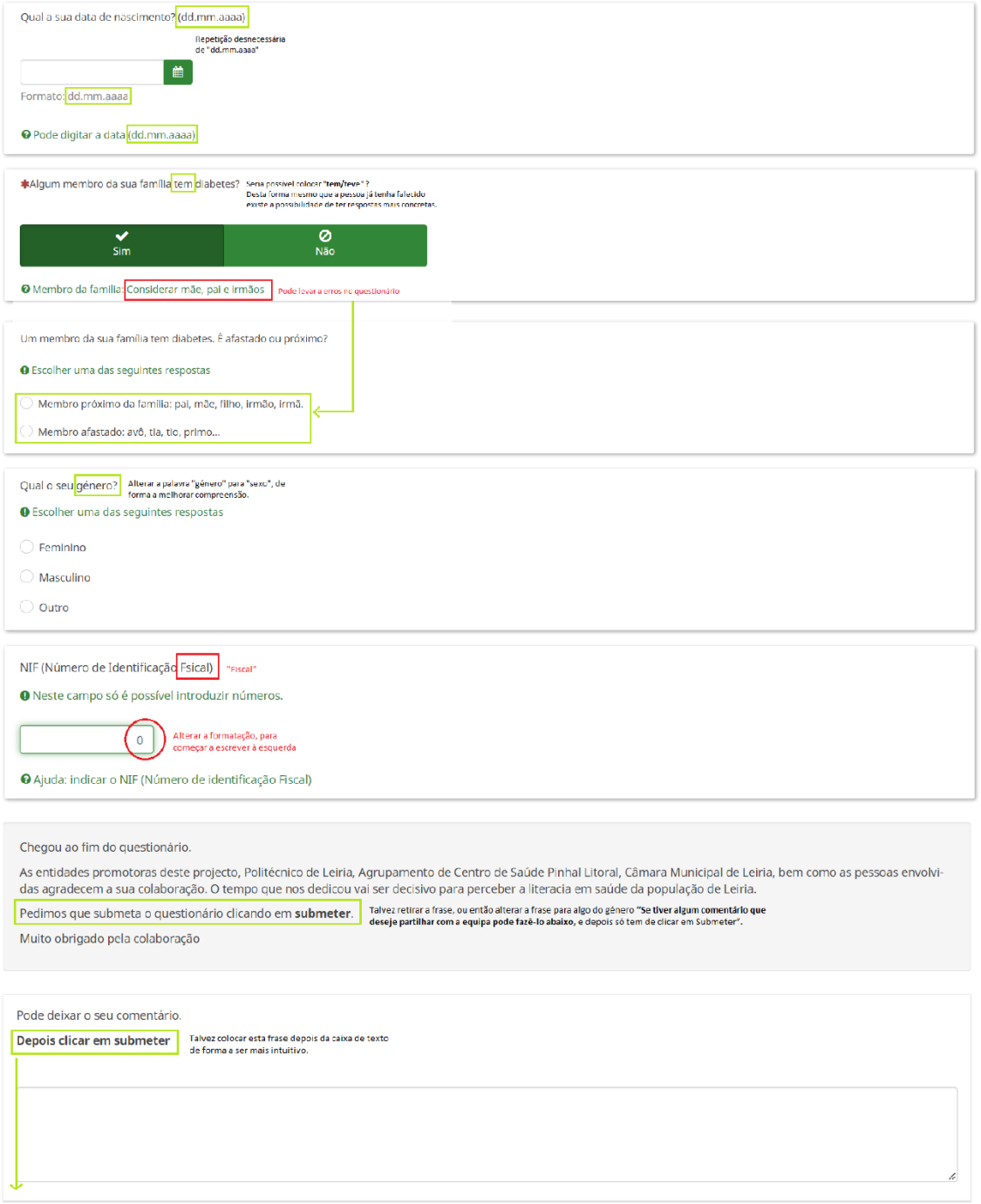


Figure 5.3 , 5.4 , 5.5 , 5.6 , 5.7 , 5.8, 5.9 Collection of changes recommended by the designers to the multidisciplinary team. Annotations in red are errors, in black and green are recommendations of minor changes.

With this methodology it was possible to find small formatting errors, flaws in the answers and errors created by the program used ("limesurvey") [Figures 5.3 to 5.9]. In addition, it was possible to find that the time to solve the questionnaire should be reduced, if possible, by reducing the number of questions. This happened months after the usability testing, when a 16-question health literacy questionnaire was validated in Portugal. Considering that the

testing phase was over before this adoption - which reduced the total number of questions from 106 to 80 - the questionnaire that the population will find during LISA implementation will be different from the one tested.

5.2. Interviews

Interviews were the second method to be implemented, and involved two distinct groups, one being experts and the other a sample of the resident population of Leiria. A set of questions was developed for both groups to facilitate the guiding of the interviews [Table 5.2 and 5.3]. The script was dynamic, allowing flexibility whilst creating a comfortable space for the interviewees to speak openly about their experiences, needs, expectations, and fears. That said, not every question needed to be addressed, as this would depend on the information that was communicated throughout the interview.

Table 5.2 Script for the interviews with experts (D. S. F. Marques & Netto-Rocha, in press).

Topic	Questions
Introduction	Hello, we are here on behalf of a cohort study that will take place in the county of Leiria. As planned we are here to ask you some questions related to cohort studies in order to understand what are the most common challenges and problems.
Previous experience in cohort studies	1. How many cohort studies have you been in? 2. What are the beginning processes of a study of this nature? 3. In the cohort studies you've been in, how was the communication conducted? 4. What communication materials were used? 5. How did you approach the population? 6. Is there a contact approach that produces better results? (phone, letter or door-to-door) 7. How many people did you have to approach in order to get the desired sample size? 8. In what way did you try to keep the participants motivated in the study? 9. What was the abandonment rate in the projects you've been a part of? 10. What were the common issues you've found? 11. Did you have a pre-selection process for the interviewers? 12. What type of personality is better to work door-to-door? 13. How did the teams work in the field?

Table 5.3 Script for the interviews with the population sample (D. S. F. Marques & Netto-Rocha, in press).

Topic	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	1. What is your age? 2. What is your gender? 3. What is your education level? 4. Where is your place of residency? (city, outskirts or village) 5. Can you give us your contacts in case we need to contact you again? (e-mail, phone number)
Health Literacy	1. Do you know what health literacy is? (if the answer is no, we will explain what it is) 2. What do you think your health literacy level is, from 0 to 5? (0 is low; 5 is high) 3. Would you like to increase it? 4. In what way do you think you could increase your health literacy level?
Cohort Study	1. Do you know what a cohort study is? (explain what LISA cohort study is and what it proposes to do) 2. Do you believe a study of this nature is important for the population? 3. Would you be interested and available to participate in a cohort study? 4. What would motivate you to participate in it? 5. Where would you look to find information about this study? 6. In what way do you think this study should be advertised? 7. What would be the best places for the communication of the study? (hospitals, health centres, social media, etc.) 8. How would you prefer to be contacted by the study? (phone, letter, door-to-door) 9. What would be the best schedule to reach you? (if the preferred one was by phone or door-to-door) 10. Would you be comfortable if the contact was at a late hour? (end of the afternoon) 11. In LISA cohort study, the contact will be done door-to-door, how many people should do the contact? 12. What is the appearance of a person you wouldn't mind opening your door to? 13. Would you be available to go to a different place to take part in the study? (health care centre, health units, etc.) 14. Would the possibility of performing routine exams, increase the likelihood of your participation in the study? 15. What would it take for you to remain in the study throughout it's phases? 16. What rewards would you like to receive for being an active participant of this cohort study?

Experts

The first group to be interviewed were the experts [Table 5.4], people with knowledge in the field of cohort studies in Portugal. The purpose was to understand the most common problems and challenges encountered in a cohort study in the country, and which strategies they used to fight them. Contact with the experts was made possible thanks to researchers within the multidisciplinary team. Since they were from different regions of the country, most of the interviews were conducted online.

Table 5.4 Interviewed Experts with information about their affiliations, the cohort studies in which they participated and the duration of the interview.

Name & Date	Affiliation	Cohort Studies	Time (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), Institute of Public Health of the University of Porto (ISPUP), Medical School of University of Porto, Porto, Portugal	◦ 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

The average duration of each interview was nearly one hour (60 minutes). Although one of the experts was unable to fully collaborate with us due to unforeseen circumstances, leaving the interview incomplete. During most of the interviews, it became obvious that

the challenges faced by the cohort studies were often similar, which led us to compile all the information into a list of challenges.

Sample of the Population

The second group to be interviewed was the Leiria population sample [Table 5.5]. This sample of adults, residents in Leiria was selected by the multidisciplinary team. The designers informed the need to find people with diverse characteristics, especially in age, education, and residential area. These characteristics were stated by the user groups definition method, which occurred before and after the sessions with the interviewees.

Table 5.5 Interviewed Sample of the Population with their information regarding age, gender, place of residence, duration of the interview and type of interview.

ID & Date	Age (years)	Gender	Geographic Placement	Educational Level	Time (min.)	Type of session
INT 01 15 / 12 / 21	78	Female	Village	4th grade	15	Presential
INT 02 15 / 12 / 21	22	Male	Village	Bachelor's degree	16	Presential
INT 03 15 / 12 / 21	55	Female	City	12th grade	23	Presential
INT 04 21 / 12 / 21	24	Female	City	Master's degree	18	Online
INT 05 21 / 12 / 21	24	Male	Outskirts	TESP (professional higher technical courses)	7	Online
INT 06 14 / 01 / 22	62	Female	Village	6th grade	12	Online
INT 07 19 / 01 / 22	43	Female	Outskirts	12th grade	12	Online
INT 08 19 / 01 / 22	41	Male	City	PhD	11	Online

In the interviews with the population, just as with the experts, a script was prepared. In these interviews, given that there was the possibility of sensitive data being shared, it was

necessary to sign an informed consent form[14]. This document was based on the existing document from the LISA study and was given to the interviewees at the beginning of the session. If the interview were in person, one copy, signed and dated, would be given to the interviewee and another would remain in the possession of the designers. If the interview was remote, the interviewee was asked to sign the document and forward it by email.

During the interviews [Figure 5.10 to 5.12], some part of the population had the opportunity to test the questionnaire (usability testing), receiving an extra number of questions related to their capacity of use, perception, time spent and interest. Therefore, it is possible to say that the interviews and usability testing methods occurred simultaneously. The data obtained by both methods was collected, analysed, and allowed to complete the list of challenges[15].

[14] The informed consent document can be found on **l. Informed consent for interviews** .
[15] More information in chapter **6. Outcomes** .

Figure 5.10, 5.11, 5.12 Presential interviews with the population on 15th of December 2021[16].

Lists of Challenges

The lists of challenges belong to the preliminary outcomes and are drawn from data collected in interviews with experts and with the sample of the population. The collection of data for these lists was carried out upon request from members of the multidisciplinary team of the LISA cohort study, after we identified some problems that occurred in previous cohort studies. This selection of topics also allowed the designers a quicker and more direct way to confirm data that emerged in the interviews and their repetition. Without these lists, designers would need to re-read the interviews each time a piece of information was needed (D. S. F. Marques & Netto-Rocha, n.d.).

Three lists of challenges, that might be faced by a cohort study, were designed. The first [Table 5.6] was drawn up through the designers' assumptions, based on their knowledge, common sense and from reviewing the literature. The second [Table 5.7] is derived from the information obtained in the interviews with the experts. There are also several concerns raised by the population sample during their interviews, that allowed the development of the third list [Table 5.8].

[16] The use of masks during interviews was essential due to COVID-19 restrictions.

Table 5.6 Lists of Challenges for the LISA Cohort Study, identified by different groups [Assumptions].

List of Challenges - Assumptions

- Raise participants, regardless of the type of contact used
  (i.e. door-to-door, phone calls, letter, etc.)
- Adapt the follow-up method in the following phases
  (i.e. door-to-door, phone calls, letter, etc.)
- Assure participants and interviewers safety
  (i.e. avoid scams, robberies, etc.)
- Keep the population motivated to participate and continue in the study
- Maintain the interviewers' committed to the study
- Capacitate interviewers to communicate with the population
- Provide continuous training to the interviewers
- Hire a supervisor and someone with backoffice know-how
- Decide where the questionnaire will be held
  (at participant's house, at dedicated units prepared to held the study)
- Determine how the questionnaire will be held
  (i.e. read by the interviewer and filled out by the participant, read and answered by the interviewer with the information received from the participant)
- Know the format the questionnaire will have, and the need for a plan B
  (i.e. digital, on paper)
- Understand the need for the extensive questionnaire
- Define graphic formats to be used, posters, outdoors or flyers
- Determine the area where the communication will be held
  (i.e. in a rural setting, city, etc.)
- Comprehend in what channels the communication will run
  (i.e. hospitals, healthcare facilities, coffees, etc.)

Table 5.7 Lists of Challenges for the LISA Cohort Study, identified by different groups [Experts].

Insights from Experts' interviews
◦ Clear identification of interviewers when approaching the population (i.e. badge, identified shirt, ID card)
◦ Have funding to ensure that interviewers will be paid (will keep them engaged to the study and motivated to continue their contribute)
◦ Give some sort of compensation to the participants (will motivate them to remain in the study)
◦ Provide training for the interviewers
◦ Use physical communication formats to build trust in the study (i.e. flyers, posters, etc.)
◦ Give feedback to the participants to keeps them engaged
◦ Inform all the staff of the study organizing entities about the study, so there is no conflicting information
◦ Supervisors of the study must be paid
◦ Have someone working in the backoffice
◦ Have an interviewer's handbook
◦ Understand that there is a steep drop in participants with every interval of the study
◦ Know that there is a higher success rate in raising participants door to door than by cell phone
◦ Recognise that to raise X participants it is necessary to go to 10X doors
◦ Keep interview time to 30 minutes maximum when in person, and to 15 minutes when done by phone

Table 5.8 Lists of Challenges for the LISA Cohort Study, identified by different groups [Population sample].

Insights from Population's interviews

- Acknowledge that majority of the population does not know the term, or what is a Cohort Study
- Understand that the population needs to be motivated to obtain more knowledge regarding health
- Recognise that the population prefers that the first contact is done through letter or email
- Value the recommendation that the communication should be done in social media, healthcare facilities and in affluent places of the region (i.e. coffee shops, pharmacies, etc.)
- Understand that the preferable contact time is late in the afternoon, before dinner time, and on the Saturday afternoons
- Realise that the majority of the interviewed people would accept to commute, if it does not overlap with working hours
- Acknowledge that if commute becomes an option, routine tests will be needed to make up for it
- Give access to the feedback, and information about how the participants contribution will affect the study
- Comprehend the preference for two interviewers, specifically one male and one female, with polished appearance and proper identification
- Grasp that a door-to-door study can be hindered by the typology of the building (i.e. condominiums)
- Perceive that the population might be suspicious, when the contact is done door-to-door
- Identify the ideal compensation/rewards for participation in the study (Interviewees recommended discounts to enter cultural events/places, free parking in the city centre, and coupons to use at local stores)

From these lists [Table 5.6 to 5.8] it was possible to understand that some of the challenges brought up by the experts were also indicated in some of the consulted publications. The compilation of all that information allowed the designers to understand and extrapolate the key elements for a successful cohort study (D. S. F. Marques & Netto-Rocha, in press):

1. Have a suitable large and diverse population sample, that can represent the entire population.
2. Keep both the team members and participants motivated and engaged in the study, because of the loss of follow-up from one phase to the next.
3. Create communication and advertisement adequate to the target population, accounting for the socio-economic differences and literacy levels.
4. Capacitate team members to adapt according to each participant characteristics.
5. Develop the study based on an attractive purpose to engage everyone that has a part in it.

5.3. User Group Definition

The user groups definition method aimed to organize people into categories to understand the distribution of the adult population of the county of Leiria. The population would be distinguished according to 4 characteristics: gender ('male', 'female' and 'nonbinary'), age groups ('18 to 29 years', '30 to 44 years', '45 to 64 years' and 'more than 65 years'), education ('Elementary', 'High school', 'Bachelor', 'Master' and 'PhD'), and place of residence ('Rural', 'Outskirts' and 'City'). Figure 5.13 shows the initial assumption of the population distribution:

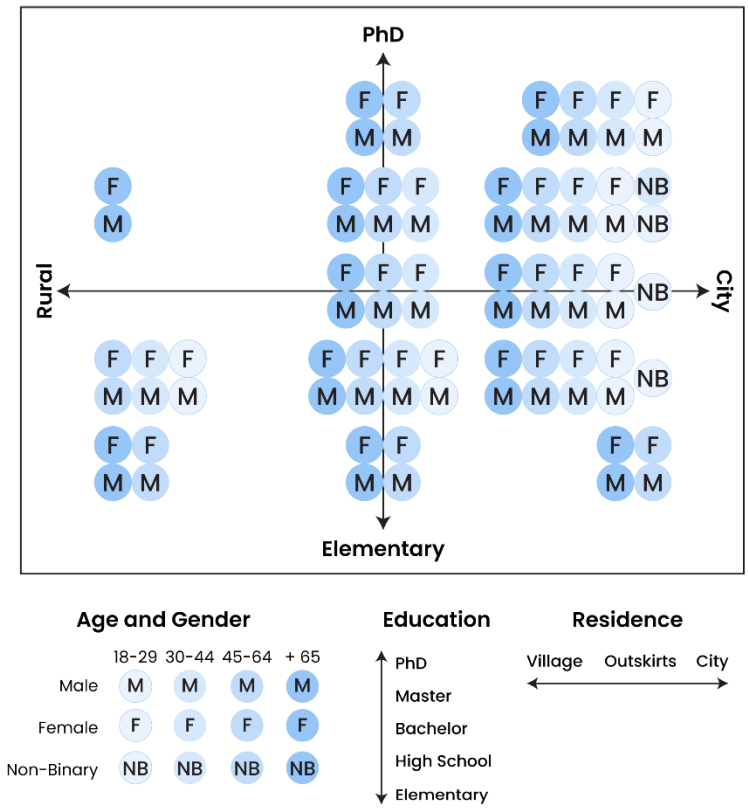


Figure 5.13 Assumption of population distribution in the county of Leiria.

The figure above was made by the designers, based on demographic graphs from the LISA cohort study[17] and assumptions of geographical distribution. This is purely qualitative rather than quantitative, as the data is sensitive and difficult to obtain. Also, it is necessary to realise that this population mapping addresses only possible respondents to the LISA questionnaire, requiring an awareness of inclusion and exclusion in the study itself (must

[17] More information in sub-chapter 2.3. Health Literacy Cohort Study in Leiria .

be over 18 years of age, have a fiscal address in the county of Leiria, speak and understand Portuguese).

This method, like the usability testing, is related to the population interviews. At the end of each interview, the assumption map was shown to the interviewees. At that moment, we would ask if what was shown was part of their reality, identifying the errors. At the end of the validation and after collecting the information from the interviewees, the map was changed, serving as a support to the cohort study [Figure 5.14].

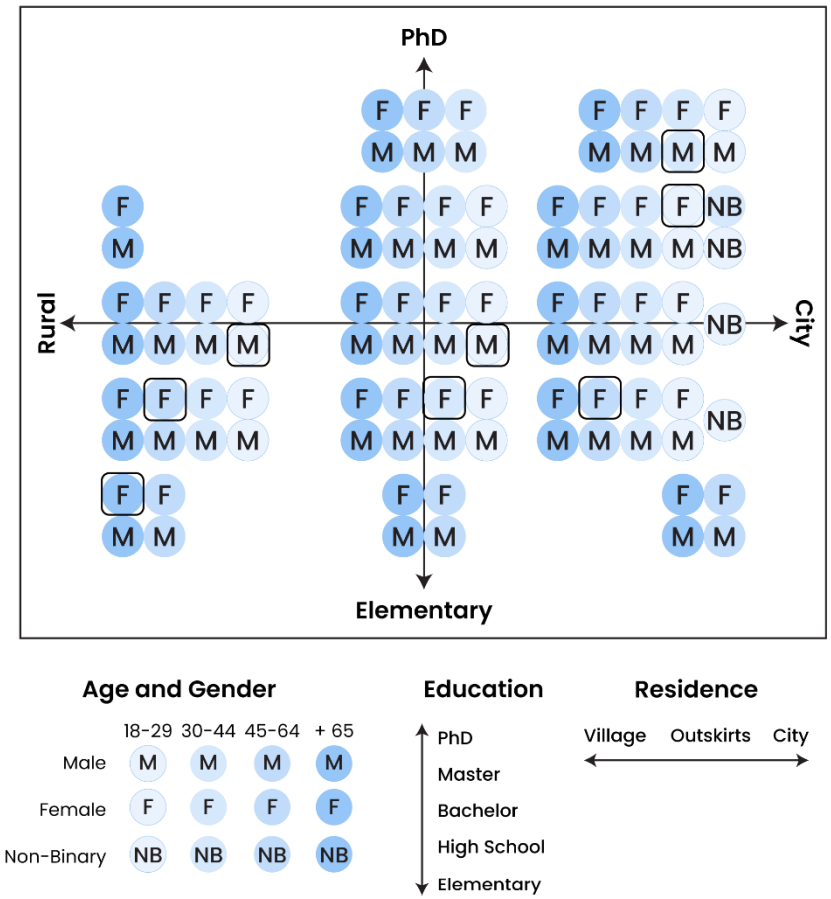


Figure 5.14 Validated document of the distribution of the population in the county of Leiria.[18]

5.4. Workshops

The workshop approach came from the need to connect the stakeholders of the multidisciplinary team with the design team, allowing them the opportunity to express

[18] Despite the validation of this graphic, it is important to inform that the population sample selected was not sufficient to cover all the educational sectors in each zone. In this way, some of the groups might be under-represented, especially regarding the population residing in the rural area.

their ideas for the LISA study during the implementation of design methods. In addition, this method allowed the team to understand the need to anticipate all the steps and possible problems the LISA study might face during its implementation. Thus, two service design approaches were incorporated in the workshops, the service blueprint, and the red and green feedback. For both workshops a moderator's guide was created with all the necessary structuring and information about materials and content to be used[19].

The initial idea was that at least one representative from each association/organising body of the LISA cohort study would be present in the workshops. These representatives should be chosen by the organisation itself, according to the individual availability to participate actively in the workshops [Table 5.9]. The presence of a designer as a participant was waived as all designers involved in the project were aware of the development and objectives of the workshop, which could lead to a pre-preparation of responses and create a bias in the responses. The participants of the LISA study (adult population of the county of Leiria) will not be part of the workshop, since the study population will be randomly selected. To include them, the inputs given by the sample of the population during the interviews were used.

Table 5.9 Attendance of the Institution representatives (stakeholders) in the workshops.

ID	Institution	Workshops Attendance	
		Service Blueprint	Red & Green Feedback
ST. 01	ACES Pinhal Litoral	Present	Not Available
ST. 02	ACES Pinhal Litoral	Present	Present
ST. 03	CML	Present	Present
ST. 04	CML	Present	Present
ST. 05	ciTechCare	Present	Present
ST. 06	ciTechCare	Present	Present

Service Design Blueprint

The objectives of the service blueprint workshop were to design a prediction of the implementation of the LISA study, from the moment interviewers were selected until the

[19] For additional information consult the appendices **d. Report – "Service Blueprint" Workshop** and **f. Report – "Red and Green Feedback" Workshop** .

end of their interaction with the participants (adult population living in the municipality of Leiria), and to organize the interactions with the population to anticipate the possible actions of the interviewers, which will be placed in the interviewers' manual/guidebook. Therefore, the workshop was called "Workshop for Structuring the LISA Cohort Study".

The workshop contained two sessions and was conducted on May 19th, 2022, at ciTechCare [Figures 5.16 to 5.19]. The two sessions were scheduled to last one hour each, with each step of the workshop - corresponding to a stage that the LISA cohort study will go through - lasting around 10 minutes. Throughout the sessions, and with the knowledge that the participants acquired in each of the phases, the process became faster and more efficient, without the need for intervention by the designers, who in this case played the role of moderators.

To conduct the workshop in a face-to-face setting some preparation was required, which took 10 minutes. It was necessary to reorganise the room, place the device for video recording in a place that allowed an overview of the room, participants, and answers, and glue the identification papers of each stage of the service blueprint on the board. In front of the participants were placed stickers of 5 different colours, pre-identified with the significance [Figure 5.15]. The preparation of the second session took advantage of all this prior arrangement, and it was only necessary to collect all the stickers from the first session and replace the steps placed on the board.

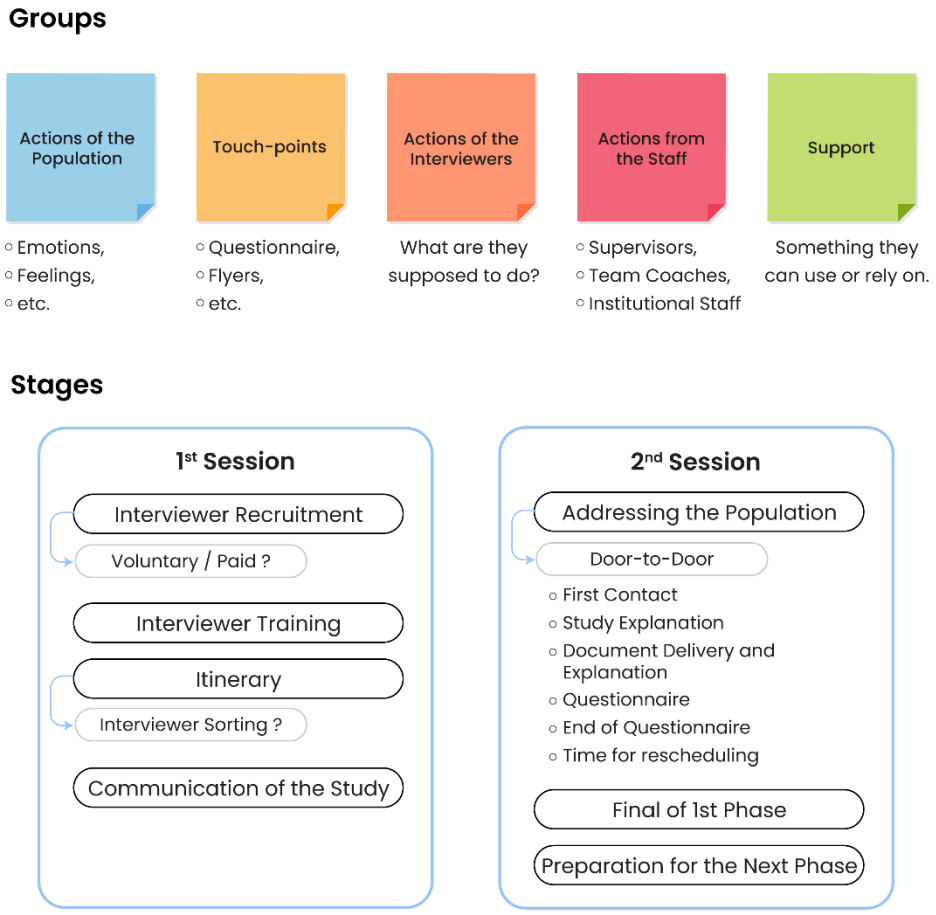


Figure 5.15 Groups and phases of the service blueprint workshop.

At the beginning of the workshop the moderator explained what the stages of the first session would be, and the general purpose. Then the colours of the stickers were clarified, with a cheat sheet so that the participants knew what to choose. In addition, the moderator indicated that the workshop would take place as an open discussion, so that everyone could give their opinion. The moderator went on presenting the stages of the Service Blueprint, and the participants' " job" was always the same, to reflect on the needs of the LISA study, and to anticipate some of the possible occurrences.

While monitoring the time, the designers collect the stickers with information after the discussion of each stage, affixing them to the board so that the participants could visualise the progress of their work. At the end of the first session participants were asked to stand up and check that what they had written was in the right places, and if there were any missing information, they could still add it - which they did [Figure 5.20].

Figure 5.16, 5.17, 5.18, 5.19 Explanation of the workshop, participants brainstorming, collection of ideas and final discussion (from left to right, and top to bottom).

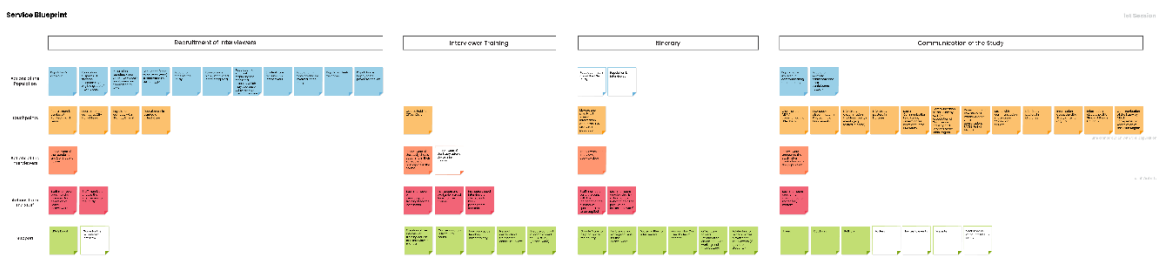
Between sessions there was a short break to change the "scenario". After the intermission the moderator explained again the main objective of the workshop, and as the participants were already familiar with the process, the second session took place without significant difficulty. Sometimes it was required that the moderator intervened to raise some issues that might be being missed by the participants. At the end of this session, participants were again invited to stand up to confirm their answers [Figure 5.21]. With the validation from these participants (stakeholders) through these open discussions and reflections, the workshop was concluded.

Figure 5.20 Visual presentation of the first session.

Figure 5.21 Visualization of the second session.

Analysis and Results

The resultant Service Blueprint was analysed, translated to a digital format, and shared with the whole multidisciplinary team of LISA in the Teams platform [Figure 5.22]. This allowed the multidisciplinary team to access the co-created Service Blueprint.



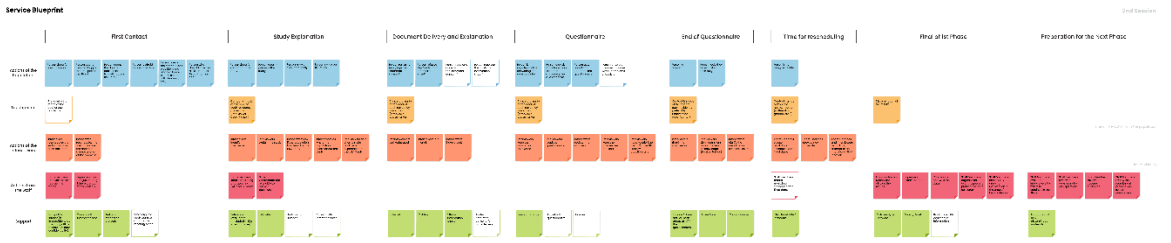


Figure 5.22 The extent of the two sessions of the Service Blueprint Workshop (digital version).

These digital versions[20] [Figure 5.22] allow an understanding of how each of the phases should be developed and what needs to happen for the LISA study to be successful. In some of the phases there are white coloured stickers, which contain information forgotten at the time of the workshop and mentioned later in meetings with the multidisciplinary team. These stickers provide a more realistic view, thus ensuring a more detailed service blueprint.

Considering the whole process of this workshop and its outcomes (the digital service blueprint) some conclusions were drawn:

- In future workshops designers should be careful about the size of the room they choose to conduct the workshop and the distance participants will be from the board (where the feedback is displayed).
- Given that most of the participants were quite familiar with the LISA cohort study and their role in its preparation, they may have forgotten to mention some key facts.
- It was noticeable that there was a different approach in the communication of ideas, which may have been due to their personality.
- It would be better to have another helper to collect the stickers, or take photos, so that the moderator would be more attentive to these "shy" participants.
- Having someone that wasn't actively present in the study preparation to participate in the workshop brought new insight and raised new questions, which was beneficial.
- The open discussion done during the workshop helped to avoid having a pile of stickers with the same information, and in some ways even enabled participants to come up with new ideas about what could still be changed in the LISA study.
- The estimated time for the workshop was respected, even with the existing delays.

[20] This information can be found in more detail in the appendix **c. Service Blueprint Workshop** .

- The attendance of more than one representative per institution allowed more people to contribute with ideas.
- The workshop on "personas" (Red and Green Feedback) had not yet been held, so there were some doubts regarding the role of interviewers and their recruitment.
- A positive thing was to have carried out this workshop firstly, and to have continued with the participants for the next one, because then they had time to add some new insights to the service blueprint.

Red and Green Feedback

The red and green feedback workshop, called "Workshop for Validation of the Personas Method" had as objectives the validation of the developed method of personas based on information gathered from interviews with the population and experts, the identification of the ideal profile for interviewers, team coaches and supervisor for the LISA Cohort Study, and the preview of the best way to find and reach individuals to perform these roles. It is important to highlight that the development of this workshop was dependent on the persona's method carried out by Constança Netto-Rocha.

The workshop followed a collaborative face-to-face format, in which the two designers assumed the role of moderators [Figure 5.23 and 5.24]. This workshop took place on the same day and in the same space as the previous one (19 May 2022, at ciTechCare), so its preparation was quick, about 5 minutes. During this time three sheets of A3 paper, each with developed persona types for the interviewer position, were pasted on the wall to facilitate the group discussion that would take place at the end. A small infographic representation of the job hierarchy (as previously presented in the LISA study chapter) was drawn on the board as well. In front of the participants were placed two pages of A4 paper, with the information about the first persona (paid interviewer) and ten stickers, one green and one red in front of each participant's seat.

The workshop started with an explanation of the objectives and how they would be achieved. Each participant was given a green and a red stickers note, on which they could write their opinion, after reflecting individually on each of the personas presented. The red stickers note was for participants to write what they disagreed about the profile. The green stickers note was for them to write what they agreed with, or something they considered essential to be included in the profile. During this explanation, the moderator also explained the importance of carrying out the workshop in silence, contrary to what had happened in the previous one, so that everyone could give their honest opinion, without being influenced, even if that opinion did not align or concur with what the other participants believed.

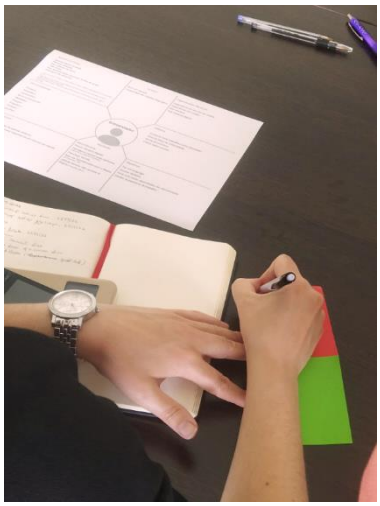


Figure 5.23, 5.24 Explanation of the personas created for the interviewer profile by Constança Netto-Rocha, and participants brainstorming (from left to right).

After this step, the moderator (Daniela Marques) passed the floor to her colleague Constança Netto-Rocha who explained the first created persona, the paid interviewer. After this explanation, the participants wrote what they thought was good and/or bad on the stickers provided. The stickers were handed to the moderator when time was up (around 5 minutes), and stuck next to the profile A3, for future discussion. Once this stage was completed, more stickers and A4 pages with information about the next persona were distributed to the participants. The remaining steps proceeded in the same way, and the remaining A3 sheets with the Team Coach and Supervisor profiles were also pasted on the wall [Figures 5.25 to 5.27].

After collecting the stickers with the feedback on the last persona presented (volunteer supervisor), the moderator invited the participants to stand up and contemplate the wall

which contained all the information about the personas and the feedback provided. The participants were also invited to consider if there was anything they found that needed to be changed or that was left out. They were also asked what the ideal profiles for each of these positions should be. After the answers, and the open discussion, the moderator concluded the workshop.

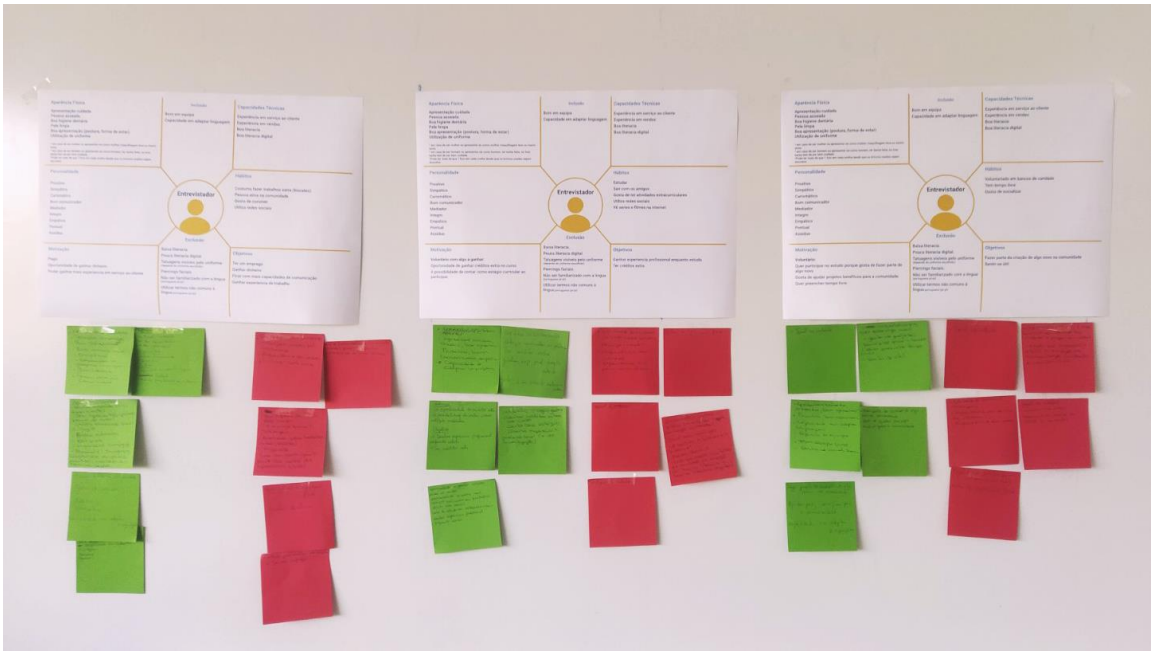


Figure 5.25, 5.26, 5.27 Personas validation through workshop with the stakeholders.

Analysis and Results

The workshop "Validation of personas" took approximately one hour, less than the planned time (1h30) and the feedback gathered, similarly to the previous workshop, was transferred to a digital format so that it could be accessible to the whole multidisciplinary team [Figure 5.28]. This access to the digital and visual outcome of the workshop also allowed my colleague to rectify the personas model created for each position (Interviewer, Team Coach and Supervisor) and helped to define the characteristics that the study should look for each of the above-mentioned roles.

To better comprehend the outcome of this workshop, it was analysed with the use of the "google sheets" tool. The data from each of the stickers was transcribed into a cell. The cells were organized, to belong in each of the previous groups portraited in the original "persona". Noticing that some of the mentioned feedback was repeated, the number of mentions was placed in front of each cell. In the end, it was possible to create infographics with all the information cleaned [Figure 5.29 and Figure 5.30].

Figure 5.28 Digital collection of stickers with "Red and Green Feedback" about each persona.[21]

[21] This information can be found in more detail in the appendix **e. Red and Green Feedback Workshop** .

Figure 5.29 Infographic with the Green Feedback.

Figure 5.30 Infographic with Red Feedback.

Based on these infographics [Figure 5.29 and Figure 5.30] it's possible to understand the important characteristics each one of the personas should contain. In example at the red feedback, most of the participants didn't agree with the necessity for the interviewers and team coaches to cover their tattoos neither with the need of having experience in customer service or sales. If we observe the green feedback infographic, the data is more disperse, since the participants only wrote the characteristics, they thought were truly essential. The best example is that all participants agreed that the paid team coach should be good at managing teams.

Based on all this process some conclusions were drawn:

- For future workshops of this nature, it is advised not to put the information in front of the participants before explaining its purpose, since participants are curious!
- The personas created were very similar in all the characteristics described, which may have facilitated and decreased the response time of the participants.
- The similarity somewhat cancelled out the need for explanation, which started to be merely " this one is identical to the other, only these changes...", making the workshop very repetitive, and not very captivating. This led to participants often using the phrase "just like the previous one" when giving negative feedback.
- Moreover, on the same topic, the personas should have been more distinct among themselves, which would help to obtain more information about the ideal profile.
- Since participants were highly focused on the same groups of characteristics, they may have lacked the opportunity to look as much at the inclusion and exclusion criteria, not having had much discussion about it.
- Perhaps it would have made it easier for the participants if each topic had been numbered, that way they wouldn't have taken so long to write down what they did and did not agree with.
- The estimated time for the workshop was not all taken up, which pleased the participants.
- The presence of more than one representative from each institution allowed more people to share ideas.

To complement this list of conclusions, the designers also gathered information about the participants thoughts on the ideal profile for each position. The profiles should be a volunteer interviewer with something to gain (student with free use of bicycle), a volunteer team coach (retired people, volunteers with spare time or senior students) and a volunteer supervisor with something to gain (CML employee or Master's student with a scholarship from IPL). Despite this, all participants agreed that in an ideal study all job positions should be paid. The information and definition of these ideal profiles helped in the development of the interviewer's manual, in which there is information for all the interviewers, team coaches, supervisors and even for the LISA multidisciplinary team, to orient them when conducting the training sessions.

5.5. Plan B

Throughout the design process, we were also developing Plan B. As described above, Plan B emerged after several meetings with the multidisciplinary team, where the value of communication in a cohort study was shown. When referring to communication, it is not only the one which is done for the dissemination of the study, but also that which was carried out within the team itself.

To communicate with the multidisciplinary team, especially with the stakeholders, the designers felt it was imperative that, in addition to the meetings, there should be a platform that everyone could access. Hence, a virtual channel was created on the Teams platform that allowed the sharing of information, documents, and the existence of meetings within the same channel. This platform was chosen due to the ease of access.

In addition to the chosen platform, the designers created presentations during the entire course of the cohort study preliminary phase, to communicate, to the rest of the team, what would be developed or implemented in the near future. These presentations contained little descriptive information, being much more visual, requiring explanation by the designers with a language that was accessible and perceptive by the whole team. These presentations included the communication strategy[22] - in which the budget and all the necessary logistics for the communication materials appeared - and the presentation of the communication materials in mock-ups[23].

Related to the dissemination, graphic materials for printing, digital materials and the branding of the LISA study were developed. As previously discussed[24], the name LISA emerged from meetings with the multidisciplinary team, and it is part of this communication process. The next sections will explain the whole process of obtaining the dissemination media, including the logo created.

[22] The presentation can be found in the appendix **i. LISA's work plan** .
[23] More information about the communication materials mockups can be found in section **Development of Communication Materials** .
[24] Additional information in chapter **2. Cohort Studies** .

Logo Development

The development of a logo followed the definition and choice of a name for the cohort study. As described previously, for this project, neither the communication nor the logo was supposed to be produced, and I reinvent this idea because only one of the design students involved in this project had previous knowledge and experience regarding graphic design and logo creation. Thus, to enable both designers to work collaboratively, a foundation for co-design was created on a platform called Figma [Figure 5.31]. This space allowed both designers to be creative in the process individually, with space for sketches, which would then be assembled for a mutual decision on the best representation for the study.

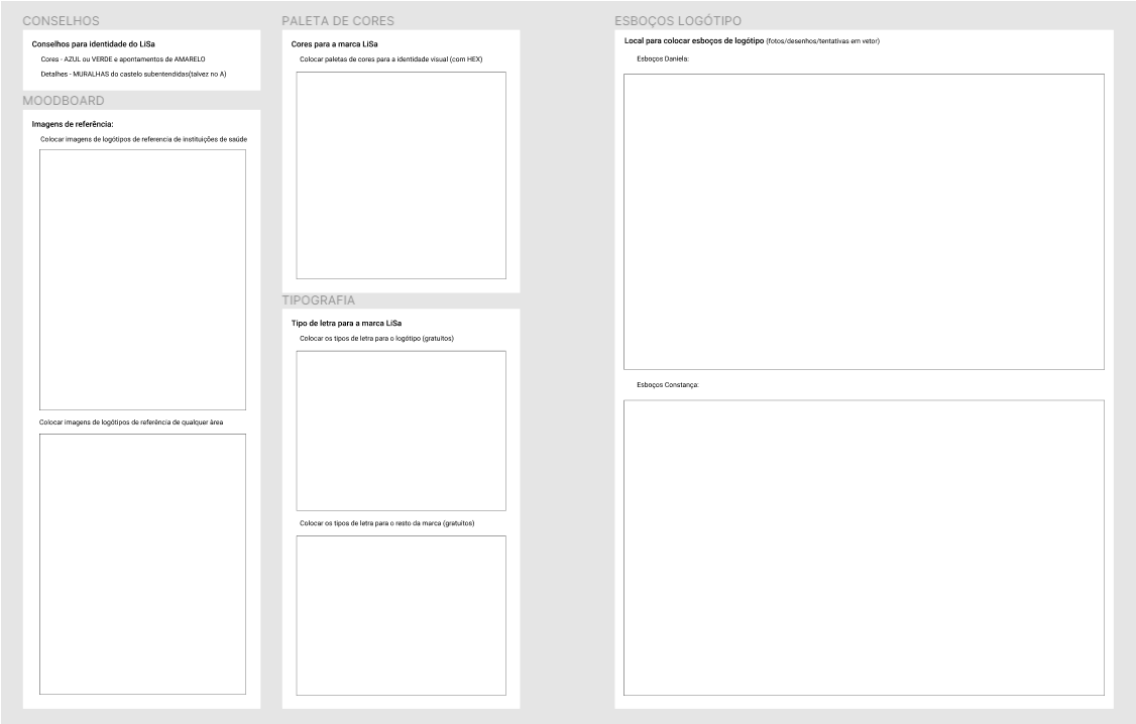


Figure 5.31 Foundation for co-designing the logo of LISA.

Therefore, the steps for the development of the cohort study logo included:

1. Definition of the name (which was already defined).
2. Research of cohort study logos and reference images unrelated to the health area.
3. Selection of colour palette and typeface.
4. Analogue and digital sketches for the logo.
5. Validation by stakeholders.
6. Public presentation of logo.

The first step, that of deciding on an appropriate name for the cohort study, had already been carried out previously by the multidisciplinary team, as was outlined in the cohort study chapter. Hence, it was responsibility of the designers to carry out the following steps. The research and collection of images of cohort study logos provided an insight into what had already been done in the field, allowing us to understand what is commonly used in projects such as this. To perceive how the LISA study can fit in the industry of the Leiria area, we also gathered images of logos of companies in the area. During this step, we also research some logos that could help inspire the creation process of the LISA logo.

Thirdly, the designers collected information from the stakeholders about which colours would be most suitable for the study. The colours yellow, green, and blue were indicated as colours related to the area of health, within the context in which we operate. Blue and green are commonly used in company logos and health-related institutions (hospitals, health centres, etc.). Yellow is a colour that in Portugal is associated with the medicine course in Portuguese colleges. With this information, some colour palettes were gathered, and the final choice was the following [Figure 5.32]:

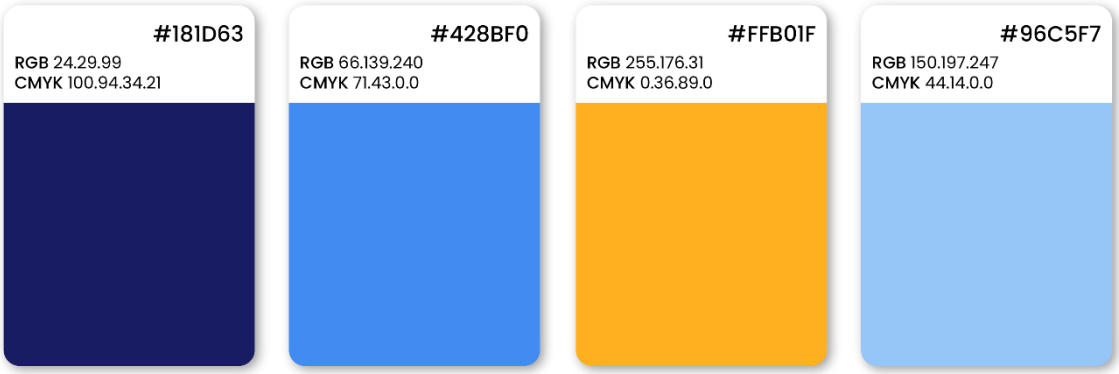


Figure 5.32 Colour Palette for the LISA cohort study.

Another part of the third step was the choice of the typeface. From the beginning, designers gathered typefaces that had a free commercial license, that were legible, and with different styles. This would allow the final design to meet all the requirements needed for the study to be disseminated without any difficulties. As a result, two typefaces were chosen: "Poppins" and "Source Serif Pro". The first one is sans serif, suitable for use in titles and for the name LISA, in lowercase format. The second one is serif, selected for the logo description or signature, and will enable readability in printed documents.

The next step in the creation of the logo, was carried out individually, with each designer sketching analogically. This allowed them to be creative with no major constraints. Then the sketches were scanned, and during meetings, discussions were held about what would be the ideal logo. In one of those meetings, using the collected images as inspiration, the designers had the idea of looking at the municipality of Leiria from a distinct perspective, focusing on patterns with cultural connotation for the population. Consequently, three emblematic places with interesting patterns were selected: the pavement of Rodrigues Lobo Square, the arcades of Leiria's Castle, and the ceiling of Leiria's Cathedral. These patterns were then digitally designed in a simplified and linear way [Figure 5.33].

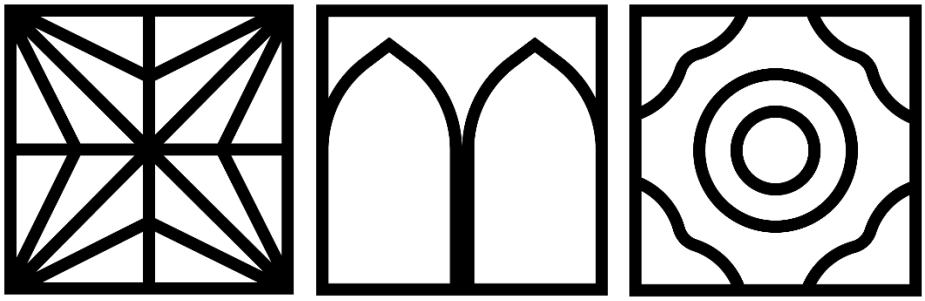


Figure 5.33 Vectors co-created based on Leiria's county emblematic places.

After these steps, and combining all the data gathered, it was possible to create a logo, which was primarily validated by the design team, with some adjustments having been made [Figure 5.34]. Subsequently, having already had a logo with all its variables - logo with signature, logo without signature, vertical logos, horizontal logos, monochrome, and polychrome logos - it was time to present it to the cohort study multidisciplinary team in order to obtain their validation[25].

Figure 5.34 LISA logotype with signature.

[25] The presentations can be found in appendix **h. LISA's brand** .

After being validated, the last step of the logo development process was its presentation to the population, which took place on 27 May 2022, during the first public presentation of the LISA cohort study. During this presentation, the logo was displayed on several physical and digital communication materials, which will be described later.

Pattern Creation

Using the three representative elements of the county of Leiria previously shown, the creation of a general pattern for the LISA study was idealized and developed. The main objective of this communication element was to provide graphic and visual cohesion between the various communication materials (Netto-Rocha & Marques, 2023).

The pattern was created using the repetition of the "icons", and the omission of some of them from time to time. Those would be either yellow or blue according to the LISA study's colour palette. Additionally, the pattern intends to allude to the traditional Portuguese tile work (Netto-Rocha & Marques, 2023) [Figure 5.35].

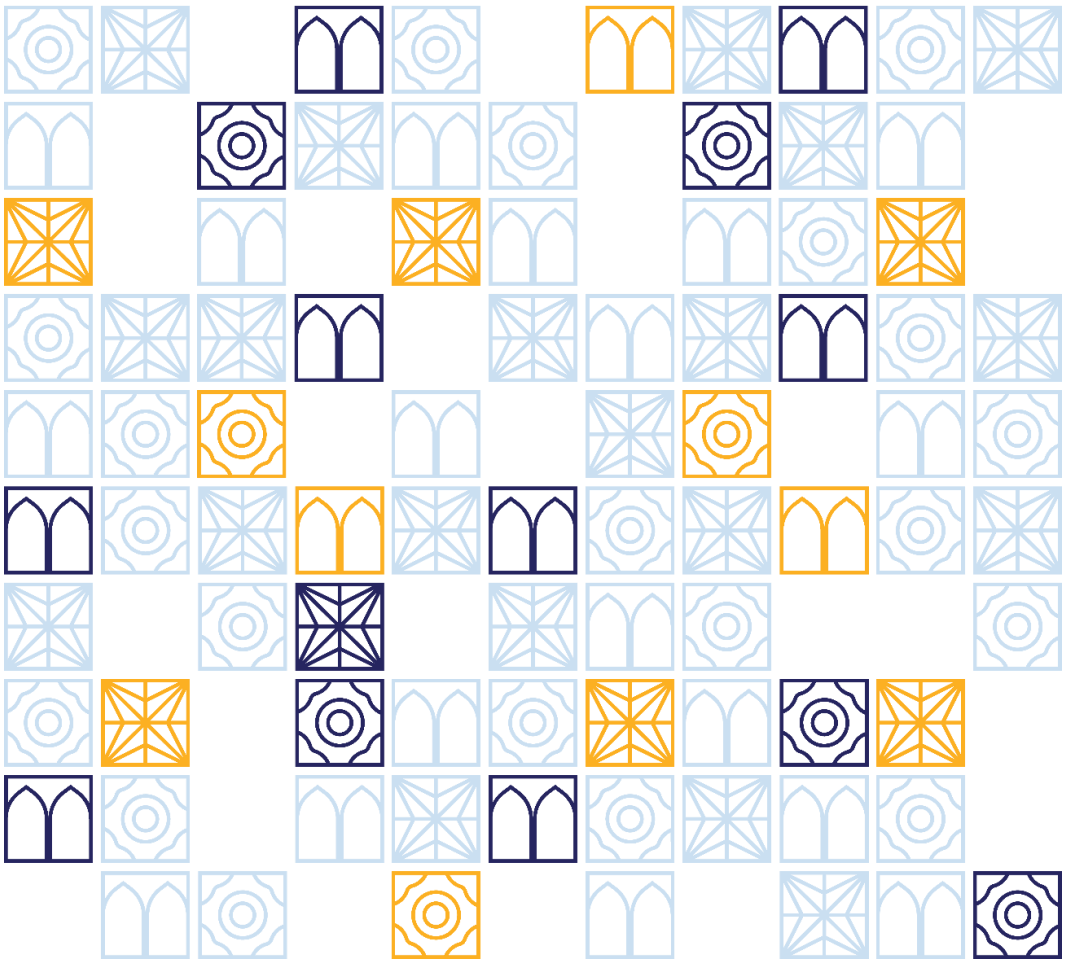


Figure 5.35 LISA's Pattern.

Development of Communication Materials

The development of communication materials was implied to be necessary during several meetings with the multidisciplinary team. Thus, the development of these communication materials was incorporated in plan B, after the development of the logo. However, before starting the development of these materials, it was necessary to understand which communication formats would be necessary for the dissemination of the LISA study and their purposes.

The idea was to develop materials that would facilitate the dissemination of information about the LISA study in diverse ways and that they would be accessible to the entire population of the municipality of Leiria. It was necessary to select both digital and printed formats, due to the information obtained during the interviews. In the digital format the most essential dissemination material was the website, which would provide all the necessary information about the LISA study, from descriptions of the study, the entities involved, the study methodology, contacts, etc. In the physical, or printed format, it would be necessary to create posters, flyers, *mupis*, outdoors, roll-ups, identification cards, t-shirts, etc. Since there were two different formats of creation, it was decided by the design team that the work would be divided. The other designer would create the layout of the website[26], while I was developing the graphics for the various printed formats.

During the development of the visuals for the printed materials, it was important to take into consideration the appropriate choice of sizes and the quantity and quality of the material. In addition, the designers needed to elaborate budgets so that the organizing and funding entities could have a vision of the values necessary for the implementation of the study. A table with some of the information described can be found below [Table 5.10]:

[26] The designer needed to develop two different layouts, because of the indecisiveness of website hosting. For more information consult the master's dissertation of Constança Netto-Rocha.

Table 5.10 Budget estimation table (the price will change depending on the decisions made by the multidisciplinary team - therefore they are hidden)[27].

Material	Description	No.	Unit Price	Total Costs
Flyers	"munken lynx" paper, SRA5, medium-low (gram), full colour, double-sided printing	40 000	[redacted]	[redacted]
T-shirts	logo imprint (10x10cm) on the left side - 2 for each interviewer	64	[redacted]	[redacted]
ID Cards	laminated paper, 8 x 5cm	50	[redacted]	[redacted]
Posters (A3)	medium-low (gram), A3, full colour, one-sided printing	150	[redacted]	[redacted]
Poster (A4)	medium-low (gram), A4, full colour, one-sided printing	350	[redacted]	[redacted]
Letters	printing of the LISA logo and organising institutions logos letter has information about the study	10 000	[redacted]	[redacted]
Envelopes	printing of the LISA logo and organising institutions logos	10 000	[redacted]	[redacted]
Participation Card	8 x 5cm, medium-high (gram), full colour, double-sided printing	8 000	[redacted]	[redacted]
Muppis	adaptable size, full colour, one-sided printing	?	[redacted]	[redacted]
Outdoors	adaptable size, full colour, one-sided printing	?	[redacted]	[redacted]
Website	page in CML website or new website hosted by IPL	-	[redacted]	[redacted]
Social Media	creation of social media accounts, content posts for social media	?	[redacted]	[redacted]
Tablet	lent by IPL - 1 for 2 interviewers	16	free	free
Router	paid to operator or lent by IPL - 1 for 2 interviewers	16	[redacted]	[redacted]
Informed Consent	10 pages, A4, double-sided printing, black & white colour one for each participant	9 000	[redacted]	[redacted]
Project Management Tool	annual subscription - used to organise teams, scheduling and communication (i.e. Notion, Teams, etc.)	-	[redacted]	[redacted]

The choice of material for printing varied according to their need to be more flexible or durable. An example is the flyers in which the chosen paper was Munken Lynx and given the standard size of the material and to take advantage of its size, the flyer format was changed from A5, to SRA5. The choice of the flyer paper, was something important since this would be one of the communication materials that would be more easily accessible, needing to be resistant enough to allow folding. In the case of the posters, having the same design, the choice for A3 and A4 format or *mupi* will be done by the multidisciplinary team when it is necessary to disseminate them in public places, such as cafes, shops, schools, institutions, etc. The most distinct communication material in terms of size is the outdoor and the roll-up that needed and will need changes depending on the spot where they are

[27] This budget was created before the implementation of workshops, not being contemplated the cost of printing interviewers' handbook, logbook, and itinerary maps (if they are to be printed).

placed, because there are several formats of outdoor, and several sizes of roll-up depending on the support.

The need for large quantities of certain of these materials comes from answers that some of the experts gave during their interviews, "in order to get the considerable number of participants, we may have to knock on the doors of 10x more people(...) and the large amount isn't because of the refusals to be interviewed, the refusals are about 50%, something normal in Portugal"(Ana Rodrigues 2022, personal communication,26th January). In other words, if we want to have a representative sample of the population, we must be able to spread the information to 10x more people. Being the population sample of 4000 or so, we may have to talk to 40,000 people, until we have a good representative sample. In the **Table 5.10** it is also possible to identify printable materials, which are not directly related to the dissemination of the LISA study, whose quantities also differ due to their usefulness, those being:

- **Identification cards** - it has two visual graphic options, one with a photograph and one without. The first one facilitates the identification of the interviewers and team coaches of the LISA study during the implementation of the questionnaire to the adult population of Leiria's county. The second version was created for the representatives of the organizing entities to use when they need to advertise LISA study in events.
- **T-shirts** - (print using the logo) allows identification of the interviewers and team coaches during the implementation of the LISA questionnaire.
- **Envelopes and letters** - delivered by interviewers when contacting potential LISA participants.
- **Participation Cards** - to be handed out to LISA participants who had completed the first phase questionnaire, as a way of generating interest and a sense of belonging.

Figure 5.36, 5.37, 5.38, 5.39, 5.40, 5.41, 5.42 Mockups of LISA's communication materials.

Until now, the communication materials [Figure 5.36 to 5.42] that have been printed were the roll-up, flyers, and identification cards for the organizing entities. Those were used in the public presentation of the LISA study, on 27th May 2022 in Aldeia da Saúde and on 16th Sep 2022 in "Mostra Tecnológica – Inovação em Saúde em Coimbra" [Figure 5.43 and 5.44]. Accompanying these pieces was a presentation designed, by both designers, to explain the cohort study aims, projected throughout the duration of the event. [28]

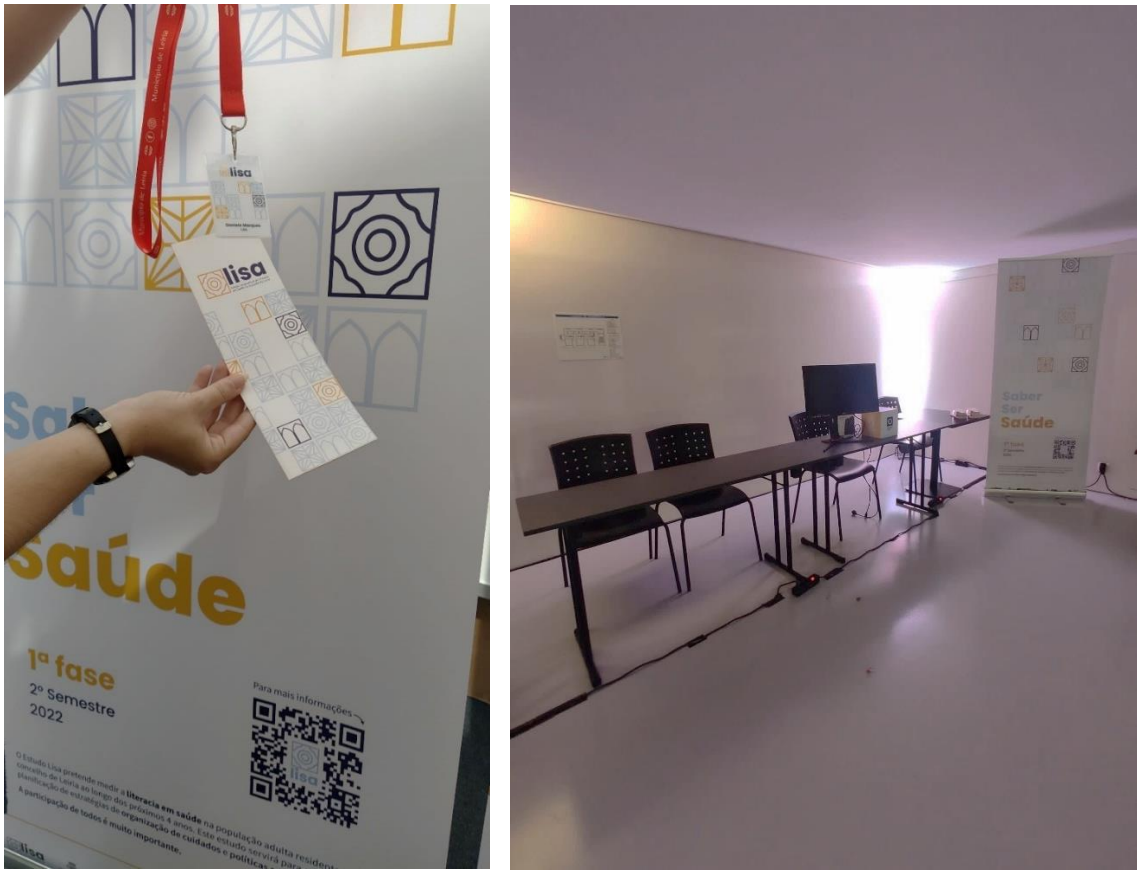


Figure 5.43, 5.44 Flyers, ID Cards and Roll-up in "Aldeia da Saúde - Leiria" (27/05/2022); Roll-up in conference "Mostra Tecnológica – Inovação em Saúde em Coimbra" (16/09/2022)

[28] The presentation can be found in the appendix **j. LISA's official announcement in "Aldeia da Saúde"** .

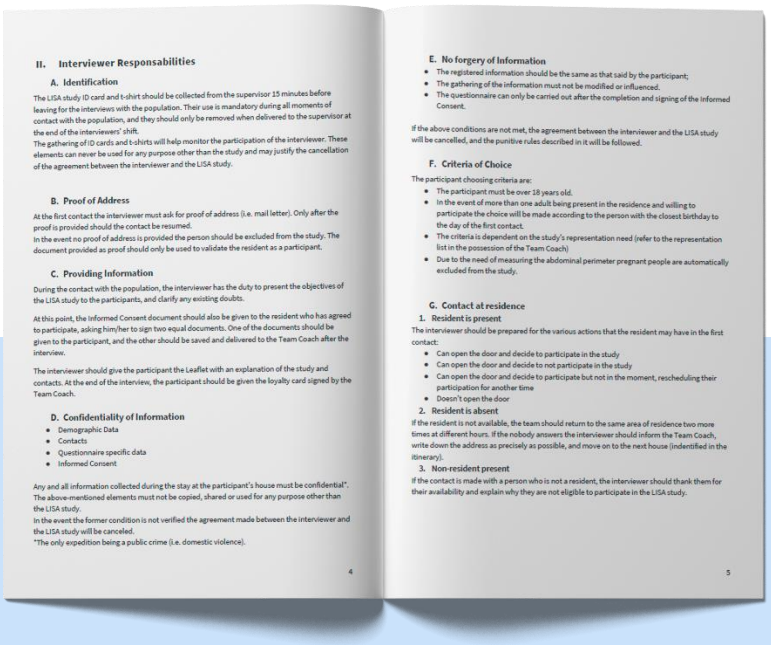
6. Outcomes

The design process and its methodologies allowed a gathering of results. Included in those are the preliminary outcomes (the lists of challenges identified in other cohort studies, the definition of an operational plan for the LISA cohort study, the results of the user groups definition and workshops) and the deliverables for the implementation of Plan B, both previously described within the design process. Besides all these outcomes, the multidisciplinary team was most enthusiastic to see the interviewers' handbook, which would allow them to create a course for the interviewers.

All these findings may vary from one cohort study to another. For that specific reason, the result of all this work should not only be related to LISA cohort study but to all cohort studies. Thus, all the processes enabled the design of a transcendent guidelines' explanation, which can be applied to the most of cohort studies.

6.1. Interviewers' Handbook

The interviewer's handbook was created in conjunction with the multidisciplinary team and aims to portray the LISA study in a clear, understandable, and accessible way for any potential interviewer. The handbook [Figure 6.1] was designed not only to be used during the interviewers' training, but also to accompany them during their interview tours in Leiria. In it, interviewers can find all the information concerning the LISA study which they may need to know in order to correctly perform their duties, such as an introduction to LISA cohort study and it's organization, a gathering of all the interviewers' and other roles' (team coach, supervisor) responsibilities, a protocol of interviewers' actions during the questionnaire and FAQ's (frequent asked questions section will be filled by each interviewer during their training). Ideally this handbook would be present in the tablets used by the interviewers on their itineraries, so it would be easy to access and sustainable.



II. Interviewer Responsabilities

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 expedition being a public crime (i.e. domestic violence).

4

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 (indentified in the itinerary).

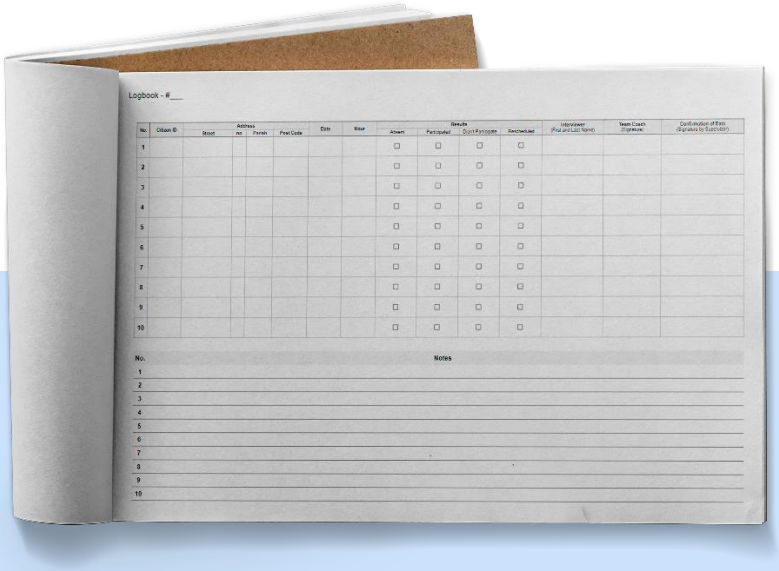
3. Non-resident present

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.

5

Figure 6.1 Interviewer's handbook visualization[29].

Besides this, the handbook is accompanied by a logbook [Figure 6.2], where each interviewer ought to note it is itinerary during the tours in Leiria. The logbook pages will then aid the supervisor and coordinator of the LISA cohort study to identify which sites have already been visited, the response from their residents, and monitor the work of each interviewer and team coach.



Logbook - #___

No.	Citizen ID	Address: Street	Address: nr.	Address: Parish	Post Code	Date	Hour	Results: Absent	Results: Participated	Results: Didn't Participate	Results: Rescheduled	Interviewer (First and Last Name)	Team Coach (Signature)	Confirmation of Data (Signature by Supervisor)
1								☐	☐	☐	☐			
2								☐	☐	☐	☐			
3								☐	☐	☐	☐			
4								☐	☐	☐	☐			
5								☐	☐	☐	☐			
6								☐	☐	☐	☐			
7								☐	☐	☐	☐			
8								☐	☐	☐	☐			
9								☐	☐	☐	☐			
10								☐	☐	☐	☐			

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

Figure 6.2 Visualization of the logbook pages.

[29] The whole interviewer's handbook can be found at a. Interviewers Handbook .

6.2. Guidelines

To finish the outcomes of this project, is a list of guidelines [Figure 6.3]. As described before, this list was created to assist in the creation and preparation of future cohort studies, despite the theme involved. The information presented as guidelines was gathered from all the research consulted and from the design process, being connected to every step of that process.

Table 6.1 List of Guidelines for Cohort Study's preparation phase.

	Guidelines
General	○ Adapt the discourse with regard to the team in which the designer is inserted, to avoid misunderstandings and preconceptions/assumptions ○ Have a communication channel available for multidisciplinary team members ○ Schedule meetings with the multidisciplinary team at least once a month (this will help to follow the schedule without deviations, and to keep everyone informed of what has been developed) ○ Define the methodology of the study to be carried out (i.e. door-to-door format, phone calls, emails, etc.) ○ Define the study audience (number of people, type of sample) ○ Define and keep the study timeline up to date ○ Create a recognisable brand with the study team (decide the name, symbol, signature, colours, typography, etc.) ○ Create printable and digital materials that will be used in the communication of the study ○ Ensure public familiarity with the study before the start of the fieldwork (i.e. advertising the study, posters, billboards, flyers) ○ Consult experts from similar studies for advice (i.e. conduct interviews with experts) ○ Select the design methodology/methodologies to be applied ○ Organise and structure the work to be carried out in the field (i.e. workshops, interviews, etc.) ○ Develop support materials for the organisation of the study (i.e. logbook, budgets, operational plan, etc.)
Oriented to LISA Cohort Study	○ Define the sample of population to be interviewed ○ Have interviews with the population that will be the target of the study ○ Test the instruments of the study with the population (in this case, the questionnaire) ○ Define the communication strategy ○ Define the organization of the field team (i.e. define the hierarchy, the roles of each one in the team, the responsibilities, etc.) ○ Define the ideal profiles of those who will contact with the population (i.e. interviewer, team coach, supervisor) ○ Create a handbook or guide to assist in the contact with the population (i.e. interviewer's handbook, logbook, etc.) ○ Develop and provide training for the field team (i.e. interviewers training) ○ Ensure that the field team is correctly identified during their shifts (i.e. t-shirts, ID cards, flyers, documents, contacts, etc.)

In this version of the list, it is possible to find some general topics that should be addressed when creating and developing any cohort study. The topics under "Oriented to LISA Cohort Study" can be used in similar cohort studies but may need to be adapted to the type of observational study. In example, if the cohort study is retrospective, then the team won't need to interview a population sample, neither will have the necessity to test instruments of the study. On the other hand, if the cohort study to be developed is prospective and close, as LISA Cohort Study, then maybe some of those points (from the "Oriented to LISA Cohort Study") can be used as a guideline.

Other version of the list of guidelines[30] is a document that differentiates the topics shown above [**Figure 6.3**] according to specific groups: the cohort study, the cohort study's team, and the designers. The document of guidelines was the version presented to the LISA's multidisciplinary team, since it focuses on the tasks each group should perform, thus highlighting the work that can be done by designers. This file when in print also allows the multidisciplinary team, in this case the LISA cohort study's team, to mark each bullet point as completed, functioning as a checklist.

Ultimately, both versions of the list are mutable, which means they are susceptible to change according to the cohort study type and theme selected. Anyway, it highlights some of the most important topics, aiding teams in the preparation phase of that study and reminding them the steps they need to ensure to build a strong and effective cohort study.

[30] The document of guidelines presented to the multidisciplinary team can be found at **b. Guidelines document** .

7. Final Considerations

Throughout this dissertation there is a constant emphasis on the designers added value by having a decision-making role in the preparation of a cohort study of this nature. To confirm the hypothesis presented before[31], the use of design methodologies can, indeed, aid the healthcare professionals and researchers on the preparatory phase of a cohort study (i.e., facilitate the communication between study's team and population, and within team members). Although besides Service Design and Participatory Design methodologies there are other methodologies that can be used. The application of User-Centered Design methodologies in the LISA cohort study was an addition to the initially defined structure and allowed for the gathering of important information for the cohort study and for the guidelines presented.

Even though the hypothesis has been verified, there were still some constraints during this project:

- One of the main obstacles was the understanding of "how a designer should be integrated in a cohort study about health literacy", since there were difficulties in finding evidence of designers in this kind of observational studies, either from experts or from the reviewed of literature. This gave the designers the need to meet with the team constantly to identify where they could facilitate the development of the study. The designers involved in LISA cohort study also realised the necessity of filling this existing gap and joined forces to attend to conferences and publish articles, some of which have been previously mentioned.

- Another difficulty that might appear in different observational studies is the management of team members' expectations about the designers' role. In this specific case, the team was inclined that designers were in the study just to do the communication materials and divulge them. It was the designers' motivations and planning skills that changed the perspectives of the team, permitting the realization of this design process.

[31] The hypothesis can be found on the chapter **1. Introduction** .

- The time at which this cohort study started may also have been a constraint, given that the preparatory phase occurred in 2021-22, while the COVID-19 pandemic was still going on. An example of that, were the difficulties in contacting people to be part of the population's sample for the interviews. If LISA had started before or after the pandemic those interviews could have been conducted differently and there could have been more people involved.

- Other potential factor that might influence this study outcomes was that the designers, despite being present at the start and preparatory phase of LISA, will not continue their work throughout the entire development of the cohort study. This can change the way the communication of LISA cohort study and the development of future stages is done, altering the expected results (i.e., the following of guidelines, the maintenance of the brand).

- Also related to the previous topic, there is the necessity to inform that due to a lack of time, a visual identity guideline to help maintaining idea of the brand could not be designed. Although the creation of this document would have been important to keep the brand equally clear in case the designers involved in the cohort study were replaced (or in this case, didn't continue to be part of the multidisciplinary team). This constraint was mainly visible when the communication for the cohort study's next phase was divulged (even if they were using the LISA's pattern, the main colours of the brand were changed).

To counteract some of these limitations, in future cohort studies (related or not to health fields) I advise the team to be multidisciplinary - to have broaden perspectives-, with designers present right from the beginning of those studies, along the development and implementation of those studies, to assist interaction with the population and between team members. I also, expect that by replicating the design process and using the guidelines mentioned in the outcomes, the teams and designers involved will rapidly and accurately plan and start the development of cohort studies, providing society more knowledge within various topics.

Concluding, even if in the beginning of this work the idealized role for a designer was only the creation of communication materials, at the moment, as a designer I can inform that being part of a multidisciplinary team and being involved in every single step of the

presented guidelines gave us, designers, a better understanding of our role, and also a new perspective about design to all the other members. The possibility of changing points of view and help changing the perspective about this recent design specialization (design for health and well-being), while contributing with new academic documentation about its role and value, was a later found motivation, and I might add, very successful.

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Appendices

a. Interviewers Handbook[32]

Estudo Longitudinal de Literacia em Saúde no Concelho de Leiria

Interviewer's Handbook

[32] The information included in this interviewer's handbook has been purposely organised for the LISA study, however, the Questionnaire chapter has been omitted from this document. To view the questionnaire, proceed to **k. LISA's questionnaire** .

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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 Responsabilities

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 expedition 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 (indentified 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 preformed 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 (indentified 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?

_____

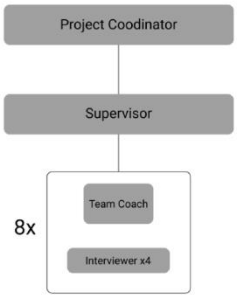
C. Information Registration

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 analized monthly to monitor their quality. This statistical analysis will be preformed 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)
- Itenerary
- Interviewer's Handbook
- Router/Hotspot
- Tablet with access to the questionnaire
- Umbrellas and waterproof trenchcoat
- Bottles of water
- Car - team's transportation throughout the itenerary
- 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	Rescheduled			
1								☐	☐	☐	☐			
2								☐	☐	☐	☐			
3								☐	☐	☐	☐			
4								☐	☐	☐	☐			
5								☐	☐	☐	☐			
6								☐	☐	☐	☐			
7								☐	☐	☐	☐			
8								☐	☐	☐	☐			
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No.	Notes
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b. Guidelines document

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

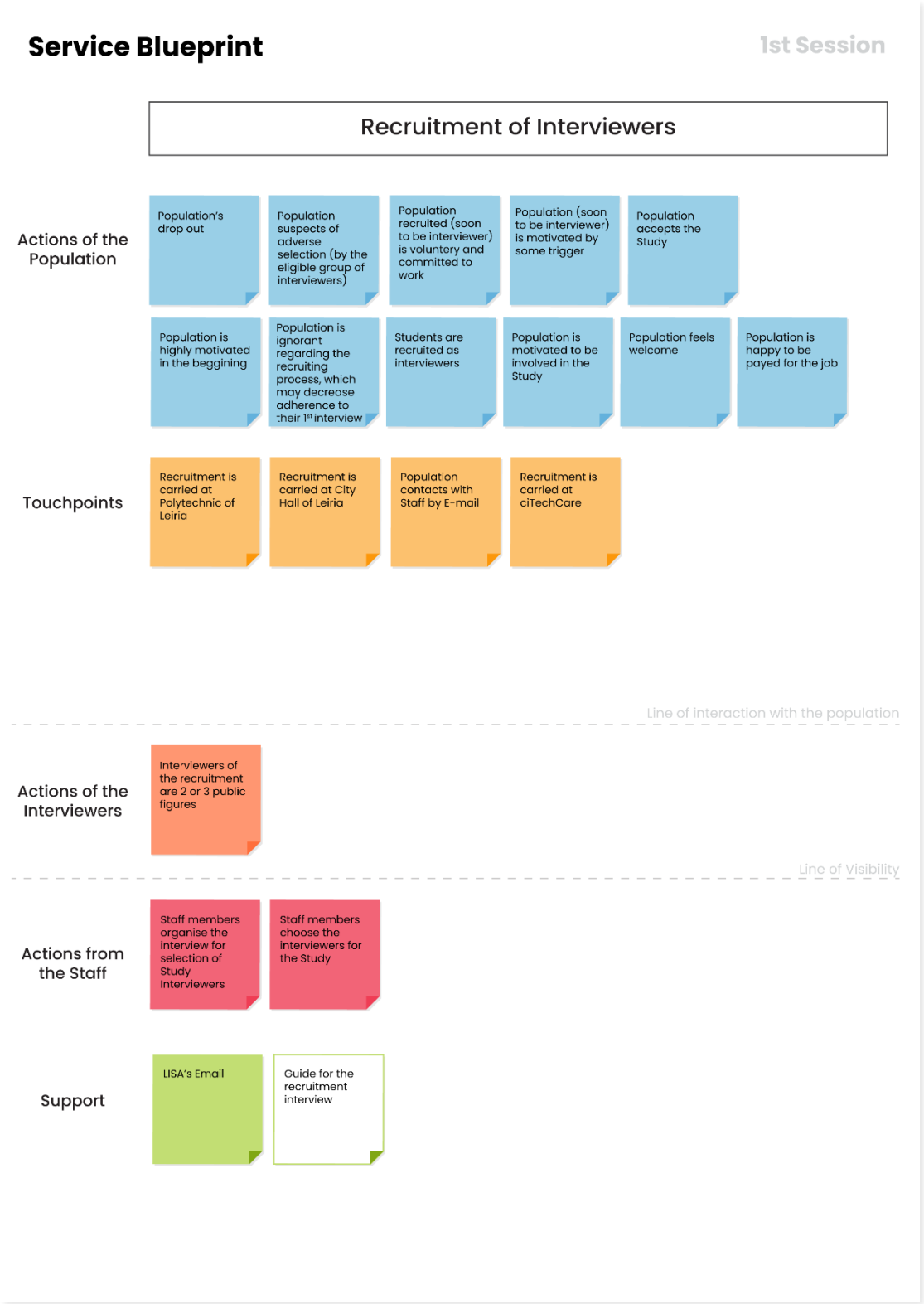
- ☐ Have a channel for internal communications between the members of the multidisciplinary team
- ☐ Schedule meetings with the multidisciplinary team at least once a month (this helps to follow the schedule without deviations, and to keep everyone informed of what has been developed)
- ☐ Structure the 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. Service Blueprint Workshop



Service Blueprint

1st Session

Interviewer Training

Actions of the Population

Touchpoints

- Course held in CiTechCare

Line of interaction with the population

Actions of the Interviewers

- Interviewers of the study should save time in their schedule to participate in the course
- Interviewers of the Study attend the training course

Line of Visibility

Actions from the Staff

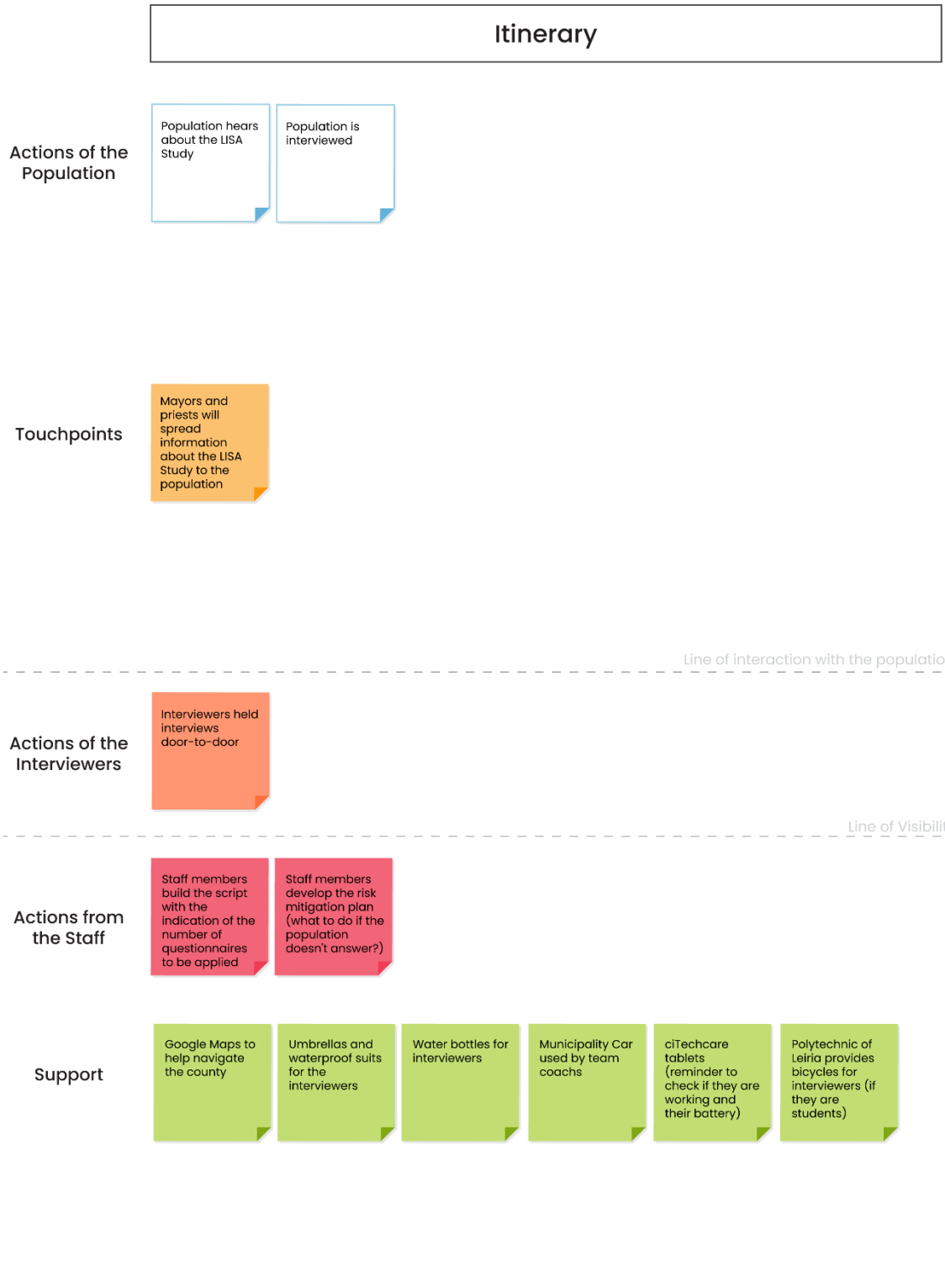
- Staff members with pedagogical training become instructors
- Instructors are available (saved time) for the course
- Instructors teach interviewers strategies to keep participants focused

Support

- Creation of the interviewer training course and Interviewers manual
- Course duration is from 6 to 8 hours
- Use roleplay as teaching methodology
- Issue of certificate of training for cohort interviews
- Execute contract of commitment to LISA study (interviewers)

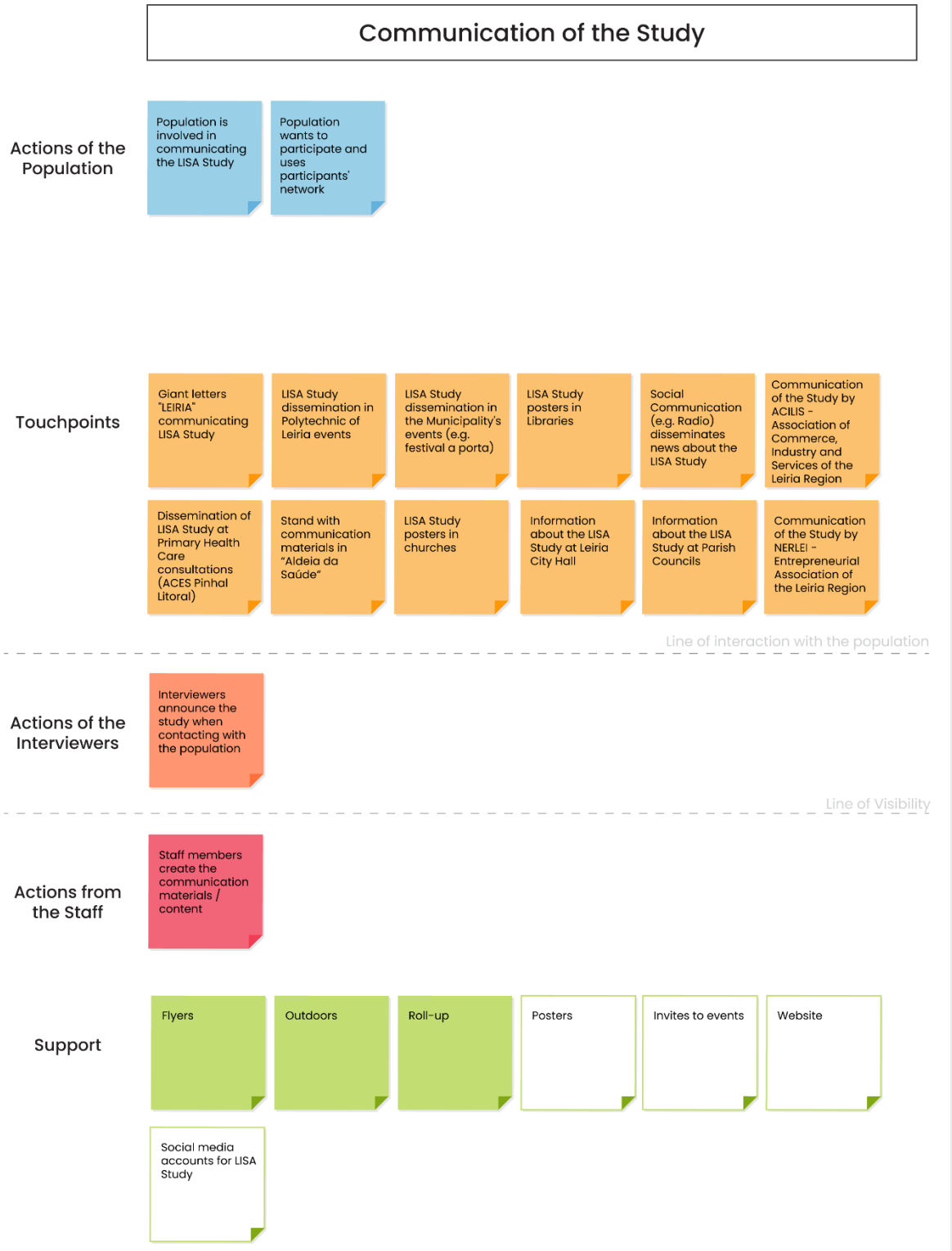
Service Blueprint

1st Session



Service Blueprint

1st Session



Service Blueprint

2nd Session

First Contact

Actions of the Population

- Person doesn't open the door
- Person opens the door happy to participate in the Study
- Person opens the door but doesn't accept to participate in the Study
- Person is afraid to open the door
- Person opens the door but isn't elegible (child alone at home, elderly person with dementia, etc.)
- Person who doen't know the NIF (Number of Fiscal Informa-tion)

Touchpoints

- First contact is made at the door of each residency

Line of interaction with the population

Actions of the Interviewers

- Interviewer reschedules the visit if they don't open the door
- Interviewer reschedules the visit if they open the door but cannot answer at the moment

Line of Visibility

Actions from the Staff

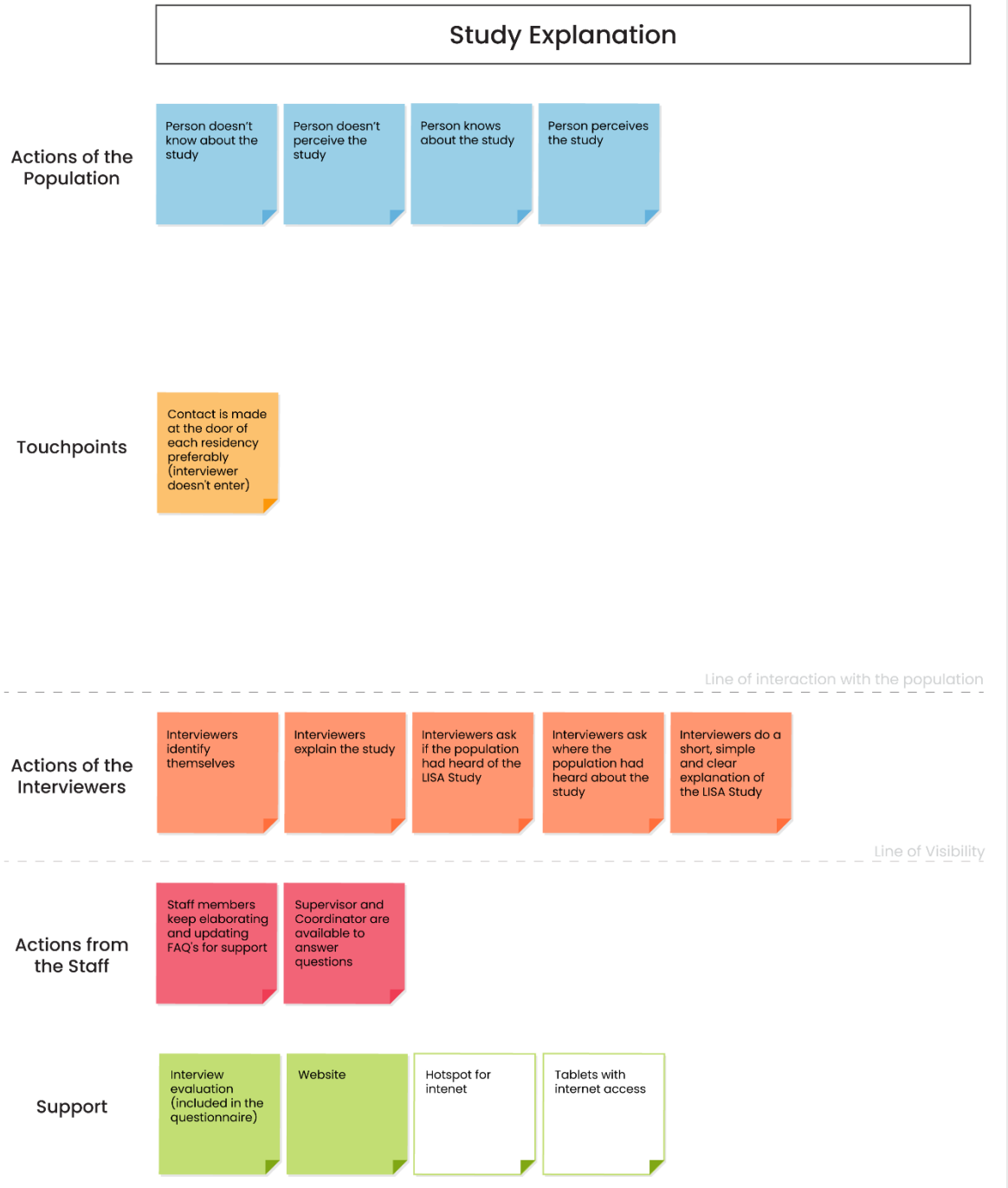
- Staff members are available to "rescue" the teams
- Supervisor can readjust routing if there are too many refusals

Support

- Hotspot for intenet (is impossible to do the study offline because of data confidentiality)
- Tablets with internet access
- Trello for managing projects
- Whatsapp for each team to arrange the meeting place

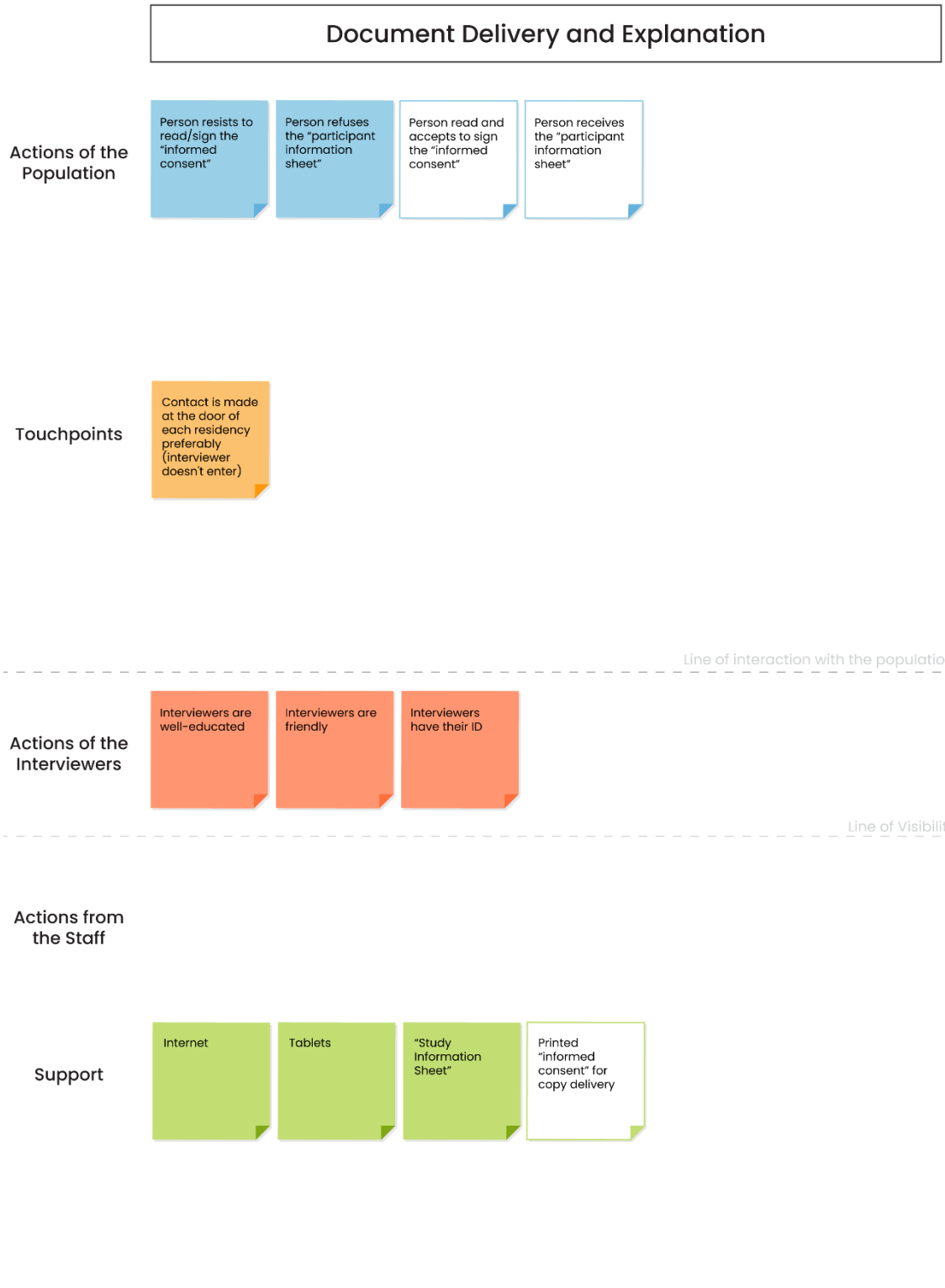
Service Blueprint

2nd Session



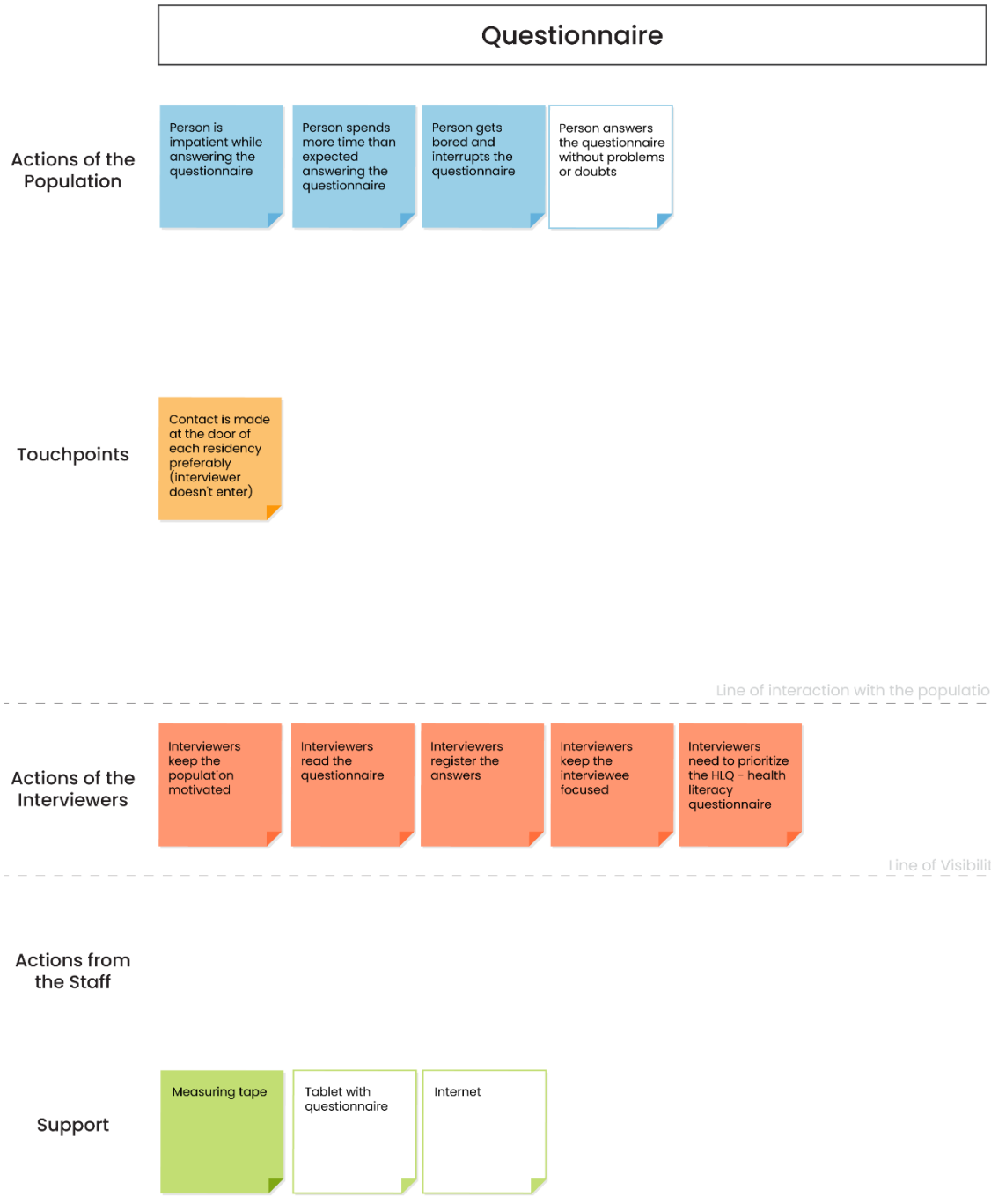
Service Blueprint

2nd Session



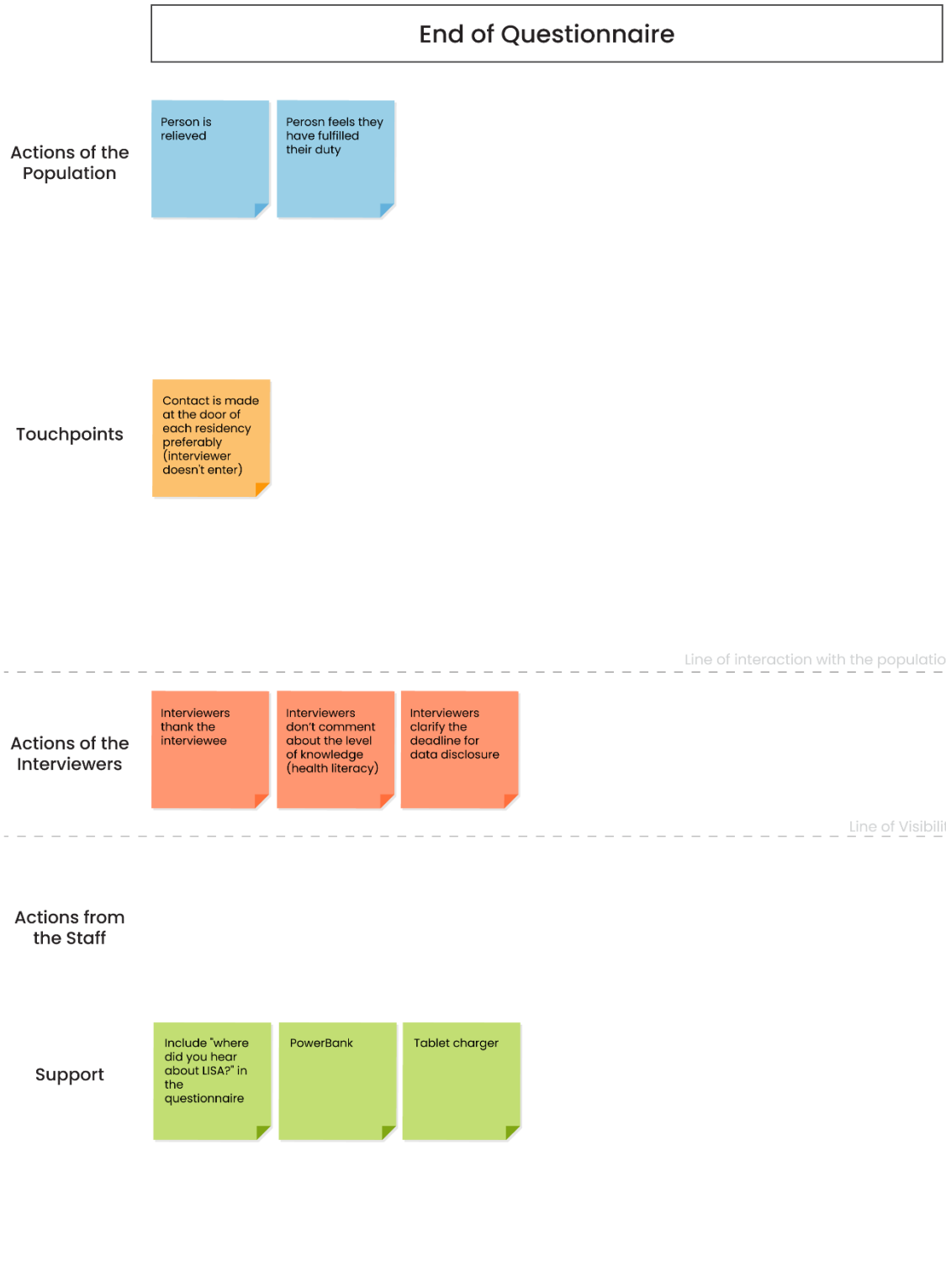
Service Blueprint

2nd Session



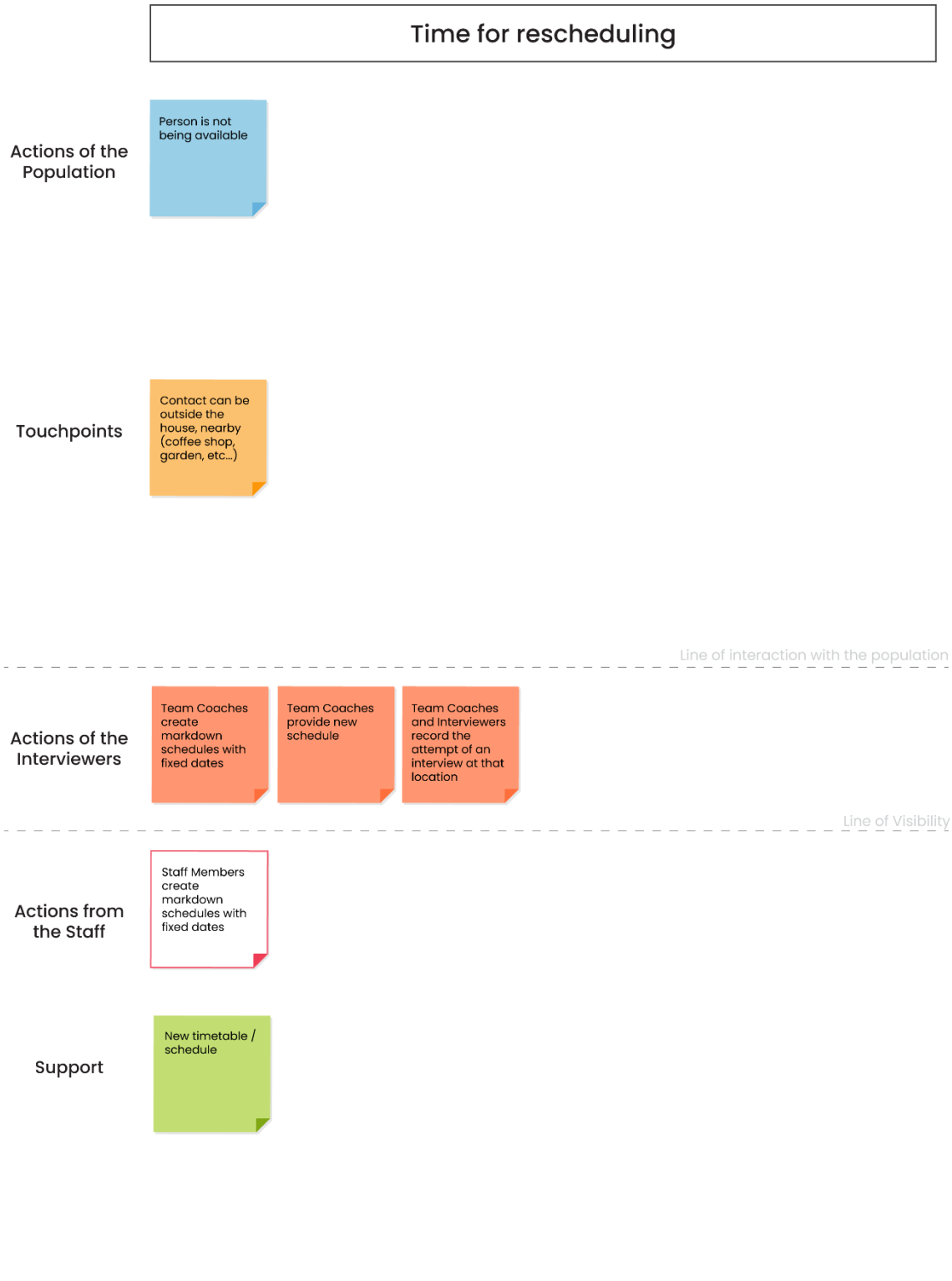
Service Blueprint

2nd Session



Service Blueprint

2nd Session



Service Blueprint

2nd Session

Final of 1st Phase

Actions of the Population

Touchpoints

- Dissemination of the results

Line of interaction with the population

Actions of the Interviewers

Line of Visibility

Actions from the Staff

- Coordinator and Supervisor divulge the results
- Supervisor "clear" the data
- Coordinator analyzes the data
- Staff Members organize an event to present publicly the data collected
- Staff Members identify key areas for intervention in the area of health literacy

Support

- Data Analysis Software
- Word / Excel
- Backoffice with confidential information

Service Blueprint

2nd Session

Preparation for the Next Phase

Actions of the Population

Touchpoints

Line of interaction with the population

Actions of the Interviewers

Line of Visibility

Actions from the Staff

- Staff Members evaluate interviewers that wants to continue in the Study
- Staff Members review the questionnaire and questions
- Staff Members review the covered territories
- Staff Members review the recruitment process and select interviewers

Support

- Elaboration of new dissemination materials

d. Report - "Service Blueprint" Workshop[33]

Autor/a: Daniela Marques
24 jun. 22

Relatório de Workshop (1)

Estruturação

Designação

Workshop de Estruturação do Estudo Coorte LISA

Objetivos

Desenhar como irá ocorrer o estudo Lisa, desde o momento em que os entrevistadores são selecionados até ao fim da sua interação com os participantes (população adulta residente no concelho de Leiria).
Organizar as interações com a população de forma a antever as possíveis ações dos entrevistadores, que serão colocadas no manual/guia dos entrevistadores.

Duração Prevista

2 sessões de 1 hora
Cada fase terá 10 minutos para ser descrita e discutida entre os participantes do workshop
Nos últimos 10 minutos de cada sessão serão discutidas as propostas e caso todos concordem serão aprovadas para serem colocadas no manual do entrevistador.

Conteúdos programáticos

Serão entregues aos participantes post-its de 5 cores diferentes, cada um representando os grupos: População, Pontos de Contacto, Entrevistadores, Staff e Suporte.
O workshop conta com onze etapas: Recrutamento de Entrevistadores, Formação de Entrevistadores, Roteiro, Comunicação do Estudo, Primeiro Contacto, Explicação do Estudo, Entrega de Documentos, Questionário, Fim do Questionário, Marcação, Final da Primeira Fase, Preparação para a próxima Fase.
O moderador do workshop irá introduzir o nome da fase (ex. Recrutamento de Entrevistadores) e os participantes irão decidir em conjunto o que poderá acontecer, cada um pode escrever nos post-its a que a cor se associa.
Nos últimos 2 minutos destinados à fase, os post-its serão colocados no quadro de visualização, onde serão apresentados e discutidos entre os participantes.
Deve haver pelo menos 2 post-its por fase. Caso os participantes do workshop achem necessário podem acrescentar-se fases.
Cada post-it não deverá ter mais do que uma ideia.
Caso a sessão 1 termine antes do tempo estipulado é possível dar inicio à sessão 2.
O moderador está habilitado a dar ideias aos participantes, mas apenas para os pontos de contacto que podem acontecer.

Metodologia

Workshop presencial colaborativo, com moderador

[33] This report is presented in Portuguese since it was made with the intent of being transmitted to the multidisciplinary team of LISA.

Autor/a: Daniela Marques
24 jun. 22

Painel de visualização (Service Blueprint as a colaborative tool - Nielsen Norman Group)

Participantes

Deve estar presente pelo menos um representante de cada associação/entidade organizadora:

- 1 investigador (ciTechCare)
- 1 médico de saúde pública (ACES Pinhal Litoral)
- 1 funcionário público (Câmara Municipal de Leiria)
- 1 enfermeiro ou TDT (Centro Hospitalar S. André - Leiria)*
- 1 designer (LIDA)**

Os participantes do estudo LISA não farão parte do workshop, uma vez que a população do estudo será selecionada de forma aleatória. De forma a incluir esta parte da população serão usados os inputs dados por representantes durante as entrevistas.

* A decisão da presença de um elemento representante do Centro Hospitalar S. André fica ao encargo da coordenadora do projeto LISA.

** A presença de um designer pode ser dispensada uma vez que todos os designers envolvidos no projeto estão a par do desenvolvimento e objetivos do workshop, o que pode levar a uma preparação prévia de respostas e criar um enviesamento das mesmas.

Material

Bloco de post-its de 5 cores diferentes, associadas a cada um dos grupos.
Computador e Projetor para apresentar as linhas base do service blueprint. Em alternativa poderá ser usado papel impresso, com o nome das etapas, colocado na mesa (neste caso será necessário ter uma mesa relativamente grande.
Uma caneta funcional para cada participante.
Uma sala disponível para a realização do workshop.
Câmara de Filmar / Tablet com tripé para gravação do workshop.
Máquina Fotográfica / Telemóvel para registar momentos durante o workshop.

Desenvolvimento do Workshop

Dados do Evento

19 de maio de 2022
14:00 às 16:10
Sala 3 do ciTechCare – Center for Innovative Care and Health Technology

Organizadores

Daniela Marques (moderadora e facilitadora)
Constança Rocha (ajudante)

Participantes

A ideia era ter presente apenas um representante de cada entidade organizadora, mas após uma conversa com a equipa ficou decidido ter dois, de forma a poder recolher mais ideias.

Autor/a: Daniela Marques
24 jun. 22

- Ana Soledade (Câmara Municipal de Leiria)
- Cátia Santos (Câmara Municipal de Leiria)
- Maria Guarino (ciTechCare)
- Rui Passadouro (ACES Pinhal Litoral)
- Sara Dias (ciTechCare)
- Tiago Gabriel (ACES Pinhal Litoral)

Programa

14:00 – Preparação da 1ª Sessão Workshop (organização do local)
14:20 – Início da 1ª Sessão e explicação sobre o desenvolvimento e objetivos do Workshop
14:30 – Discussão sobre o que deve acontecer durante a etapa de "Recrutamento de Entrevistadores"
14:40 – Discussão sobre o que deve acontecer durante a etapa de "Formação de Entrevistadores"
14:45 – Discussão sobre o que deve acontecer durante a etapa de "Roteiro"
14:55 – Discussão sobre o que deve acontecer durante a etapa de "Comunicação do Estudo"
15:10 – Término da 1ª Sessão e Preparação da 2ª Sessão Workshop (organização do local)
15:20 – Inicio da 2ª Sessão e explicação sobre o desenvolvimento do Workshop
15:22 – Discussão sobre o que deve acontecer durante a etapa de "Primeiro Contacto"
15:33 – Discussão sobre o que deve acontecer durante a etapa de "Explicação do Estudo"
15:40 – Discussão sobre o que deve acontecer durante a etapa de "Entrega de Documentos"
15:50 – Discussão sobre o que deve acontecer durante a etapa de "Questionário"
15:53 – Discussão sobre o que deve acontecer durante a etapa de "Fim do Questionário"
15:58 – Discussão sobre o que deve acontecer durante a etapa de "Marcação"
16:04 – Discussão sobre o que deve acontecer durante a etapa de "Final da Primeira Fase"
16:07 – Discussão sobre o que deve acontecer durante a etapa de "Preparação para a Próxima Fase"
16:10 – Finalização do Workshop

Sumário

Preparação

De forma a realizar o workshop de forma presencial foi necessário fazer uma preparação que durou 10 minutos. Foi preciso reorganizar a sala, colocar o dispositivo para gravação de vídeo num local que permitisse uma visão geral da sala, participantes e respostas, e colar os papeis de identificação do service blueprint no quadro. À frente dos participantes foram colocados post-its de 5 cores diferentes, previamente identificados com o significado.

A preparação da segunda sessão aproveitou todas esta organização previa, e foi apenas necessário recolher todos os post-its da primeira sessão e substituir as etapas coladas no quadro.

Autor/a: Daniela Marques
24 jun. 22

Workshop

Houve um atraso na chegada dos participantes ao citechcare, o que permitiu a preparação do local para o workshop. Quando todos os participantes estavam presentes foi possível par a moderadora Daniela Marques dar início ao workshop, começando por explicar que o mesmo iria ser dividido em duas sessões o que significava que seria importante que todos estivessem presentes durante esse tempo.

A moderadora explicou quais seriam as etapas da primeira sessão, e o objetivo geral do workshop. Explicou as cores dos post-its, tendo uma cábula para que os participantes soubessem o que escolher. Também explicou que o workshop iria decorrer de forma de discussão aberta para que todos dessem a sua opinião. A moderadora foi apresentando as etapas do Service Blueprint, sendo que o "trabalho" dos participantes era sempre o mesmo refletir sobre as necessidades que o estudo LISA, e prever alguns dos acontecimentos.

Sempre a monitorizar o tempo a moderadora e a ajudante iam recolhendo os post-its com informações após a discussão de cada etapa colando-os ao quadro para que os participantes conseguissem visualizar o seu trabalho. No fim da primeira sessão foi pedido aos participantes que se levantassem e confirmassem que o que tinham escrito estava nos locais certos e caso faltasse alguma coisa ainda estariam a tempo de a acrescentar, o que aconteceu.

Entre sessões houve um pequeno intervalo para mudança do "cenário". Após o intervalo a moderadora explicou novamente o objetivo principal do workshop, e como os participantes já estavam familiarizados com o processo, a segunda sessão ocorreu sem grandes atritos. Por vezes era necessário que a moderadora interviesse para levantar algumas questões que poderiam estar a ser esquecidas por parte dos participantes. No fim desta sessão, os participantes foram novamente convidados a levantarem-se para confirmar as suas respostas. Após esta discussão aberta e de reflexão, a moderadora deu o workshop por finalizado.

Conclusões

De todo este processo retirámos algumas conclusões:

- Em futuros workshops devemos ter cuidado com o tamanho da sala e a distância a que os participantes irão estar do quadro (ou local onde são colocadas as respostas).
- Como a maioria dos participantes estavam muito familiarizados com o estudo e com o seu papel na sua preparação, podem ter esquecido de mencionar alguns factos que podem vir a ser importantes.
- Foi visível uma diferença de comunicação entre algumas pessoas, que pode ter acontecido devido à sua personalidade.
- No futuro, seria melhor ter mais um ajudante para recolher os post-its, ou tirar fotografias, desta forma o moderador poderia estar mais atento a estes participantes "tímidos".
- Ter alguém que não tem estado tão presente no estudo a participar no workshop trouxe uma nova visão e levantou novas questões, o que é benéfico.

Autor/a: Daniela Marques
24 jun. 22

- A discussão aberta foi uma mais valia para não ter um aglomerado de post-its com a mesma informação, e de certo modo ajudou os participantes a ter novas ideias sobre o que ainda pode ser alterado no estudo LISA.
- O tempo estimado para o workshop foi cumprido, mesmo com os atrasos existentes.
- A presença de mais do que um representante por instituição permitiu que mais pessoas contribuíssem com as suas ideias.
- Como o workshop das personas ainda não tinha sido realizado, existiram algumas duvidas relativamente ao papel dos entrevistadores e do seu recrutamento.
- Algo favorável foi ter realizado este workshop em primeiro lugar, e ter continuado com os participantes para o seguinte, porque eles foram acrescentando algumas coisas ao servisse blueprint.

Podemos concluir que a realização do workshop foi muito importante e uma mais-valia para a tomada de decisões no planeamento do estudo LISA. O feedback recolhido será posteriormente analisado e ajudará as entidades organizadoras do estudo a perceber quais são os cenários com que podem ter de ser deparar durante a implementação do estudo, quais são os materiais necessários e qual pode ser o seu papel enquanto staff.

e. Red and Green Feedback Workshop

Green Feedback

Red Feedback

Interviewer (paid)

- Reason for exclusion tattoos visible through "uniform", facial piercings, opportunity to earn money
- Experience in customer service and sales

- Review physical appearance notes
- Earn money

- Wearing a uniform
- Tattoos visible through the uniform
- Experience in sales
- Use of social networks

- Tattoos visible through the uniform
- Having a job

- Good dental hygiene
- Clean skin
- Facial piercings, tattoos...
- Usually do extra work (odd jobs)
- Not paid
- (Physical appearance part of the notes)

Green Feedback

Interviewer
(volunteer with something to gain)

- Possible placement as curricular internship (student)
- Opportunity to earn extra credits (student)
- Gain work experience while studying
- Enjoy having extra-curricular activities
- Uses social media

- Possible placement as curricular internship (student)
- Opportunity to earn extra credits (student)
- Gain work experience while studying
- Enjoy having extra-curricular activities

- Clean appearance, neatness
- Thorough presentation
- Proactive
- Good communicator
- Empathetic
- Ability to adapt speech

- Possible placement as curricular internship (student)
- Opportunity to earn extra credits (student)
- Gain work experience while studying
- Enjoy having extra-curricular activities

- Volunteer with something to gain
- Opportunity to earn extra credits (student)
- Possible placement as curricular internship (student)
- Gain professional (and research) experience

Red Feedback

Interviewer
(volunteer with something to gain)

- Tattoos visible through the uniform
- Facial piercings
- Opportunity to earn money
- Experience in customer service and sales

- Review physical appearance notes

- Use of uniform
- Use of social media
- Tattoos visible through the uniform
- Experience in sales
- Experience in customer service

- Tattoos visible through the uniform
- Having a job

- Review physical appearance notes
- Go out with friends
- Watching series and films on the internet
- Social media
- Exclusion criteria (except for low literacy and low digital literacy)

Green Feedback

Interviewer (volunteer)

- Want to do something new (volunteer)
- Enjoy projects beneficial to the community
- Want to cover their spare time
- Feel useful

- Be involved in the creation of something new in the community
- Assisting projects beneficial to the community
- Ability to adapt speech

- Clean appearance
- Thorough presentation
- Proactive
- Good communicator
- Ability to adapt speech
- Want to cover their spare time
- Enjoy socialising
- Like to work in a team

- Possible placement as curricular internship (student)
- Opportunity to earn extra credits (student)
- Gain work experience while studying
- Enjoy having extra-curricular activities

- Be involved in the creation of something new in the community
- Enjoy helping projects beneficial to the community

Red Feedback

Interviewer (volunteer)

- Tattoos visible through uniform
- Facial piercings
- Opportunity to earn money
- Experience in customer service and sales

- Experience in sales
- Customer service experience
- Review physical appearance notes

- Use of uniform
- Tattoos
- Experience in customer service
- Experience in sales

- Tattoos visible through the uniform
- Having a job

- Experience in customer service and sales
- Physical appearance (except clean appearance and wearing a t-shirt)

Green Feedback

Team Coach
(paid)

- High level of literacy
- Experience in dealing with and managing teams/people
- Proactive
- Mediator
- Integrity
- Good at managing teams

- Experience in dealing with and managing teams/people
- Appearance notes (all)
- Use of terms not common to the language
- Good at managing teams
- Good at adapting speech
- Enjoy socialising

- Good presentation
- Autonomous
- Organisational
- Good at managing teams
- Active in the community

- Autonomous
- Good communicator
- Integrity
- Good at managing teams
- Possibility to gain more experience in customer service

- High level of literacy
- High level of digital literacy
- Gain work experience
- Enhance communication skills
- Good team management skills
- Ability to adapt speech
- Problem solver
- Assiduous and punctual
- Empathetic
- Friendly

Red Feedback

Team Coach
(paid)

- Tattoos visible through uniform
- Facial piercings
- Opportunity to earn money
- Customer service and sales experience

- Opportunity to earn money
- Experience in customer service
- Sales experience
- Not familiar with the language
- Tattoos visible through the uniform

- Have a driving licence
- Visible tattoos
- Experience in sales
- Experience in customer service
- Experience with management software

- Having a job
- Tattoos visible through the uniform

- Experience in customer service
- Experience in sales
- Familiarity with report writing
- Paid
- Having a job
- Earning money
- Have a driving licence

Green Feedback

Team Coach
(volunteer with something to gain)

- Graduating students / master's students / R&D scholarship holders
- Opportunity to earn extra credits (student)

- Graduating students / master's students / R&D scholarship holders
- Possible placement as curricular internship (student)
- Opportunity to earn extra credits (student)
- Ability to adapt speech

- Graduating students / master's students / R&D scholarship holders

- Possible placement as curricular internship (student)
- Opportunity to earn extra credits (student)

- Graduating students / master's students / R&D scholarship holders
- Possible placement as curricular internship (student)
- Opportunity to earn extra credits (student)
- Ability to adapt speech

Red Feedback

Team Coach
(volunteer with something to gain)

- Tattoos visible through uniform
- Facial piercings
- Opportunity to earn money
- Customer service and sales experience

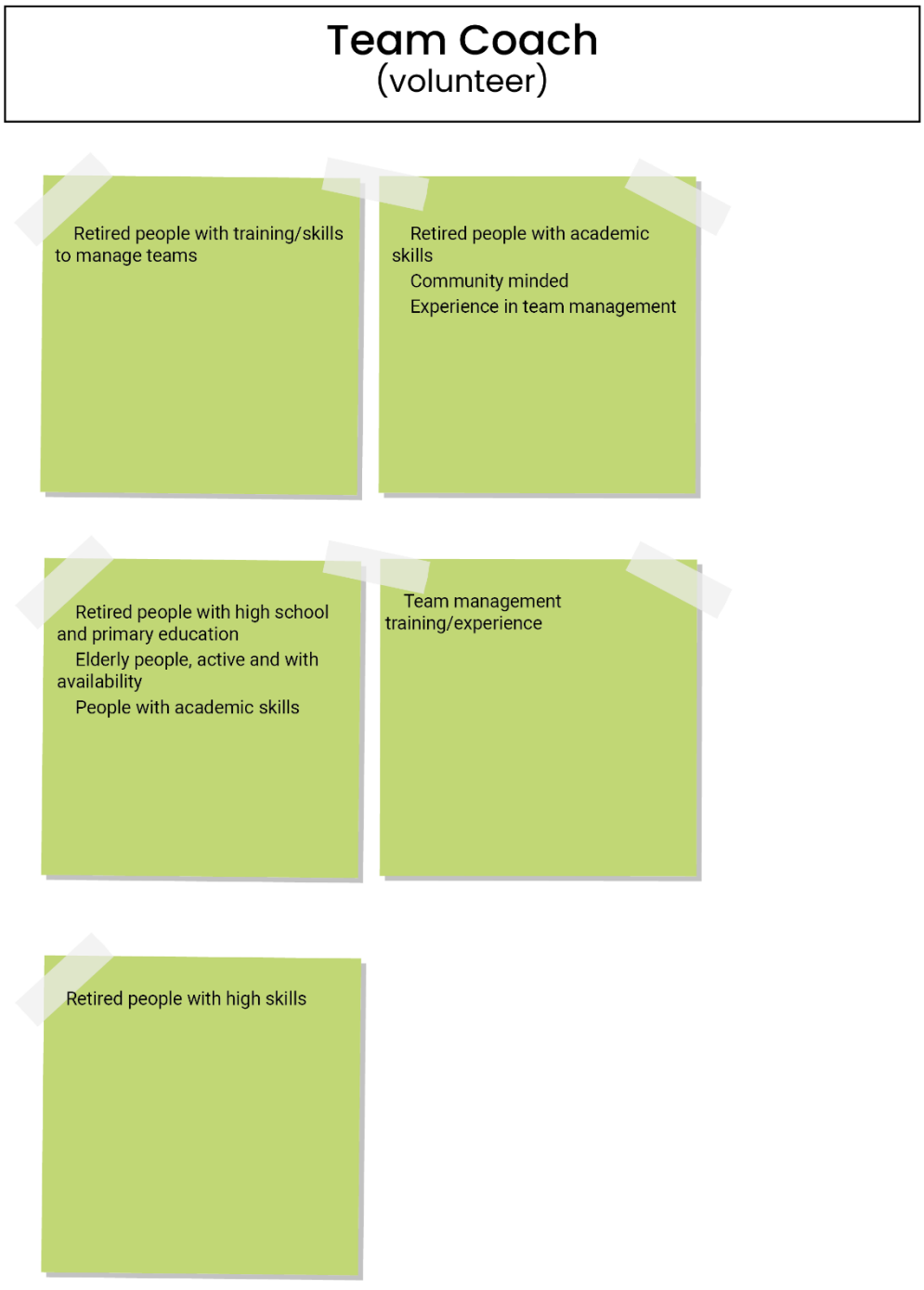
- Review physical experience notes
- Customer service experience
- Sales experience

- Students in the first year should not be included

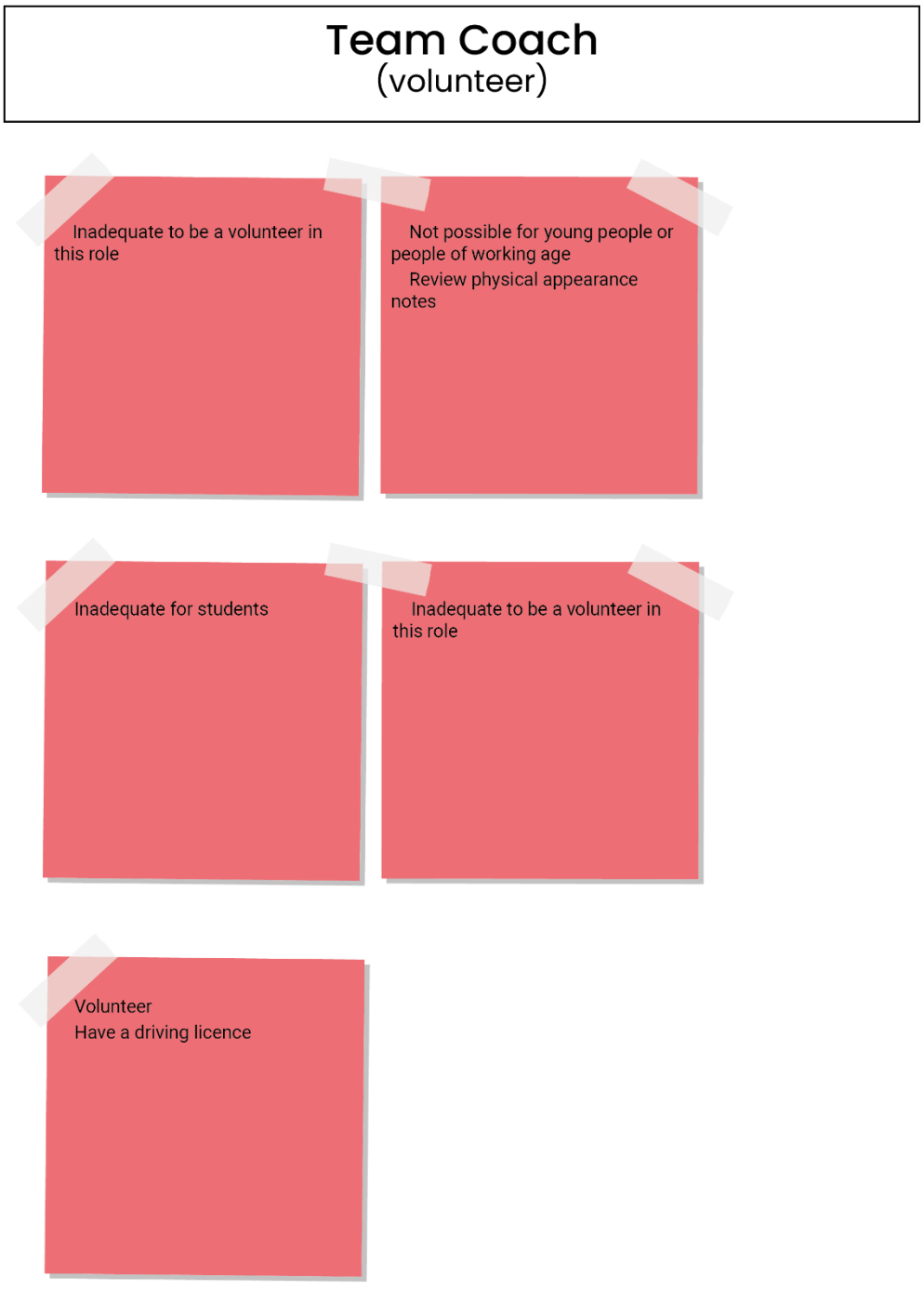
- Tattoos visible through uniform

- Technical skills (except high levels of literacy and of digital literacy)

Green Feedback



Red Feedback



Green Feedback

Supervisor
(paid)

- Experience in leading and managing teams/people
- Organisational skills
- Ability to adapt speech
- Good communicator
- Integrity

- Experience in leading and managing teams
- Good at managing teams
- Ability to adapt speech

- Good team management skills
- Organised
- Motivation to do the job and stability and maturity at work
- Experience in leading and managing teams

- Good communicator
- Good at managing teams
- Ability to plan ahead and set priorities
- Clean appearance

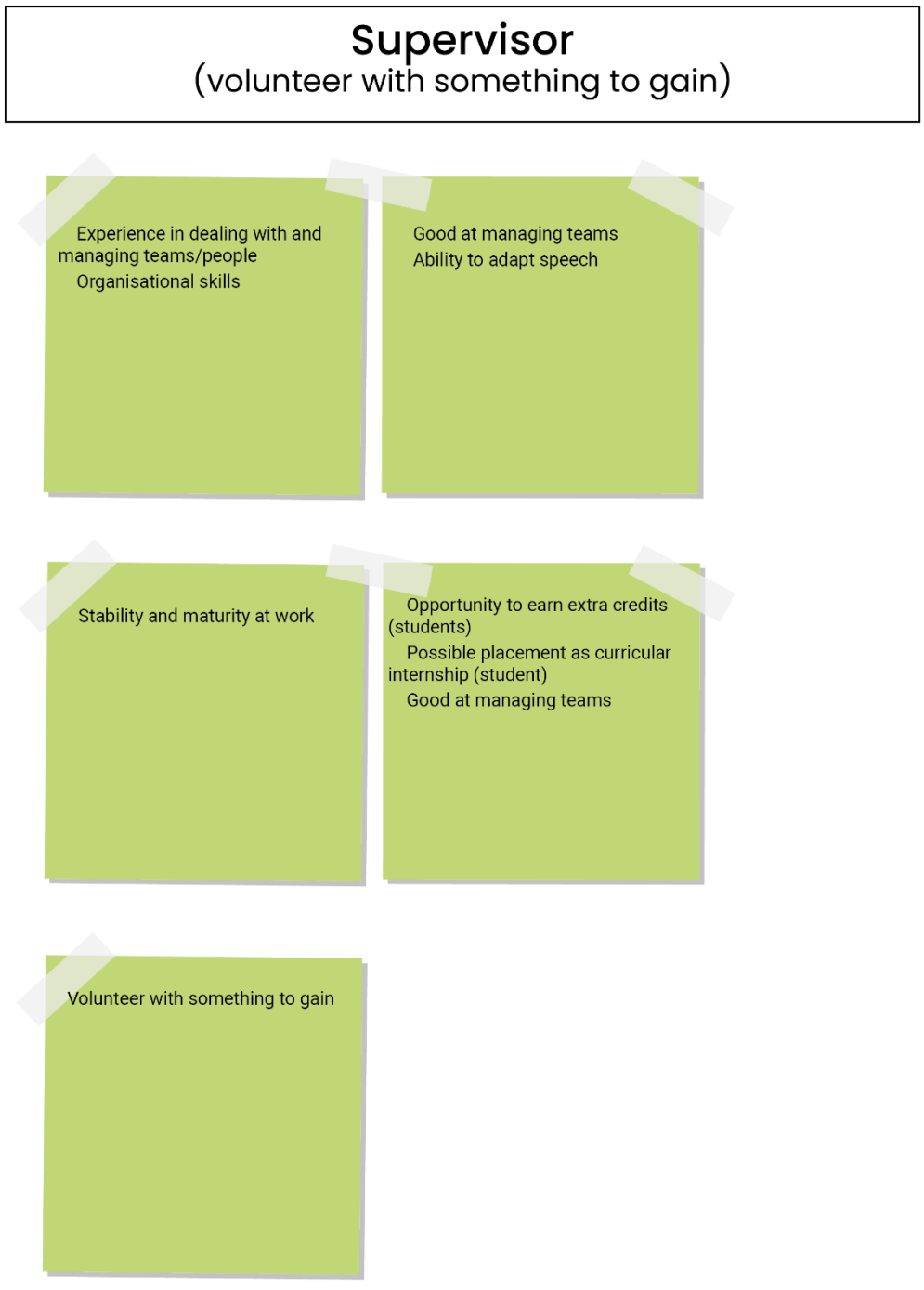
- Clean appearance
- Good at managing teams
- Have a job
- Gain work experience
- Ability to plan and prioritise
- Mediator

Red Feedback

Supervisor
(paid)

- Experience in dealing with customers
- Paid / Earned opportunity
- Use of uniform
- Experience in data management software
- Experience in dealing with clients
- Knowledge of data analysis
- Use of uniform
- Inadequate for students

Green Feedback



Red Feedback

Supervisor
(volunteer with something to gain)

Experience in dealing with customers

Use of uniform
Experience of data management software

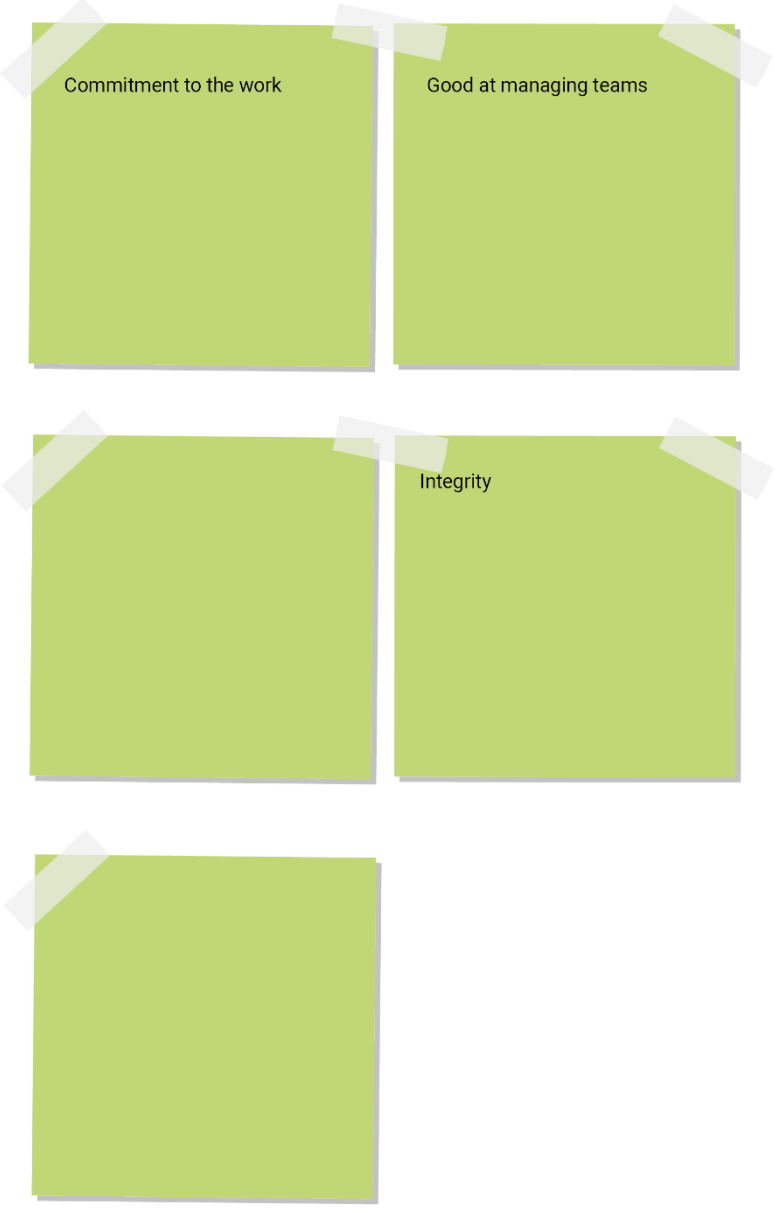
Inadequate for students (master's student can't ensure this as part of their master's degree)

Nothing to exclude

Inadequate for students

Green Feedback

Supervisor
(volunteer)



Red Feedback

Supervisor
(volunteer)

It is a very challenging position (shouldn't be a volunteer)

Must be someone paid given the responsibilities
Cannot be a volunteer
Must have a contract

I don't think we can find someone with this profile - on a voluntary basis

Lack of commitment is a strong possibility, therefore the profile is not suitable

Cannot be a volunteer

f. Report - "Red and Green Feedback" Workshop[34]

Autor/a: Daniela Marques
22 jun. 22

Relatório de Workshop (2)

Estruturação

Designação

Workshop de Validação do Método de Personas

Objetivos

Validar o método de Personas desenvolvido anteriormente com base em informações recolhidas nas entrevistas à população e a experts.
Escolher o perfil ideal do entrevistador, orientador de equipa e coordenador para o Estudo Coorte LISA.
Antever qual a melhor forma de contactar e encontrar indivíduos para ocupar estes cargos, que estejam correlacionados com o perfil ideal.

Duração Prevista

1 sessão de 1h30
A apresentação da persona ocupará no máximo 5 minutos
O feedback será escrito nos post-its em 2 minutos.
A discussão final com o feedback oferecido ocupará o restante tempo da sessão.

Conteúdos programáticos

O moderador começa o workshop apresentando os objetivos do workshop e entregando aos participantes post-its de duas cores, um representando o feedback negativo e outro representando o feedback positivo.
De seguida o moderador apresenta uma das personas desenvolvidas, descrevendo o perfil, emoções, motivações e qual o cargo a ocupar.
No momento seguinte os participantes demonstram se concordam com o perfil criado, escrevendo as suas ideias nos post-its verdes ou vermelhos.
Os post-its serão recolhidos e colocados junto ao perfil apresentado.
Este processo será repetido mais oito vezes.
No final, haverá uma discussão aberta sobre as ideias recolhidas sobre cada persona, e os ajustes que poderiam ser feitos.

Metodologia

Workshop presencial colaborativo, com moderador
Apresentação das Personas em formato físico
A metodologia de base para o workshop é Red and Green Feedback (Service Design Thinking)

[34] This report is presented in Portuguese since it was made with the intent of being transmitted to the multidisciplinary team of LISA.

Autor/a: Daniela Marques
22 jun. 22

Participantes

Deve estar presente pelo menos um representante de cada associação/entidade organizadora:

- 1 investigador (ciTechCare)
- 1 médico de saúde pública (ACES Pinhal Litoral)
- 1 funcionário público (Câmara Municipal de Leiria)
- 1 enfermeiro ou TDT (Centro Hospitalar S. André - Leiria)*
- 1 designer (LIDA)**

Os participantes do estudo LISA não farão parte do workshop, uma vez que a população do estudo será selecionada de forma aleatória. De forma a incluir esta parte da população serão usados os inputs dados por representantes durante as entrevistas.

* A decisão da presença de um elemento representante do Centro Hospitalar S. André fica ao encargo da coordenadora do projeto LISA.

** A presença de um designer pode ser dispensada uma vez que todos os designers envolvidos no projeto estão a par do desenvolvimento e objetivos do workshop, o que pode levar a uma preparação prévia de respostas e criar um enviesamento das mesmas.

Material

Bloco de post-its de 2 cores, preferencialmente verde e vermelho.
Impressão A3 de cada persona criada (9 folhas impressas).
Uma caneta funcional para cada participante.
Uma sala disponível para a realização do workshop.
Câmara de Filmar / Tablet com tripé para gravação do workshop.
Máquina Fotográfica / Telemóvel para registar momentos durante o workshop.

Desenvolvimento do Workshop

Dados do Evento

19 de maio de 2022
16:40 às 17:40
Sala 3 do ciTechCare – Center for Innovative Care and Health Technology

Organizadores

Daniela Marques (moderadora e facilitadora)
Constança Rocha (moderadora)

Participantes

A ideia era ter presente apenas um representante de cada entidade organizadora, mas após uma conversa com a equipa ficou decidido ter dois, de forma a poder recolher mais ideias.

- Ana Soledade (Câmara Municipal de Leiria)
- Cátia Santos (Câmara Municipal de Leiria)
- Maria Guarino (ciTechCare)
- Sara Dias (ciTechCare)
- Tiago Gabriel (ACES Pinhal Litoral)

Autor/a: Daniela Marques
22 jun. 22

Programa

16:30 – Preparação do Workshop (organização do local)
16:40 – Início e explicação sobre o desenvolvimento e objetivos do Workshop
16:45 – Introdução e reflexão sobre a persona "Entrevistador Pago"
16:50 – Introdução e reflexão sobre a persona "Entrevistador Voluntário com algo a ganhar"
16:55 – Introdução e reflexão sobre a persona "Entrevistador Voluntário"
17:02 – Introdução e reflexão sobre a persona "Team Coach Pago"
17:08 – Introdução e reflexão sobre a persona "Team Coach Voluntário com algo a ganhar"
17:13 – Introdução e reflexão sobre a persona "Team Coach Voluntário"
17:21 – Introdução e reflexão sobre a persona "Supervisor Pago"
17:25 – Introdução e reflexão sobre a persona "Supervisor Voluntário com algo a ganhar"
17:29 – Introdução e reflexão sobre a persona "Supervisor Voluntário"
17:32 – Discussão Aberta
17:40 – Finalização do Workshop

Sumário

Preparação

Antes de iniciar o workshop foi necessária uma pequena preparação que durou 5 minutos. Durante este tempo foram coladas três folhas A3, cada uma com os tipos de personas desenvolvidos para o cargo de entrevistador, na parede para facilitar a discussão que iria ocorrer no final. Foi também desenhado no quadro uma pequena representação infográfica da hierarquia dos cargos presente no estudo LISA. À frente dos participantes foram colocadas duas folhas A4, com a informação sobre a primeira persona (entrevistador pago) e dez post-its, um verde e um vermelho à frente do lugar de cada participante.

Workshop

Os participantes chegaram ao local do workshop, e vendo as folhas na mesa alguns leram as características da persona. Sendo isto feito sem nenhuma explicação, gerou-se algum caos e discussão porque não concordavam com os tópicos pertencentes ao bloco de aparência física. O workshop pôde começar quando a moderadora Daniela Marques recuperou a atenção dos participantes e explicou qual seria o objetivo do workshop e o papel que os participantes teriam no mesmo. Ainda houve espaço para esclarecimento de dúvidas relativamente à forma como os participantes deveriam atuar no workshop.

Depois desta etapa, a moderadora passou a palavra à colega Constança Rocha que explicou a primeira persona criada, o entrevistador pago. Após esta explicação os participantes escreveram o que achavam ser bom e/ou mau nos post-its destinados. Os post-its foram entregues à moderadora quando o tempo terminou, sendo colados junto do perfil A3, para futura discussão. Finalizada esta etapa foram distribuídos pelos participantes mais post-its e as duas folhas com informação sobre a persona seguinte.

As restantes etapas procederam da mesma forma, tendo sido colados na parede as restantes seis folhas A3 sobre as personas de Team Coach e Supervisor.

Depois de recolher os post-its com o feedback sobre a última persona apresentada (supervisor voluntário), a moderadora convidou os participantes a levantarem-se e

Autor/a: Daniela Marques
22 jun. 22

contemplarem a parede que continha informação sobre as personas e o feedback fornecido. Foi ainda perguntado aos participantes se havia algo que achavam necessidade de ser alterado, que não estivesse mencionado, e para eles enquanto grupo quais deveriam ser os perfis ideais para cada um destes cargos. Após as respostas, e a discussão aberta a moderadora deu o workshop por finalizado.

Conclusões

De todo este processo retirámos algumas conclusões:

- Em futuros workshops deste tipo não é aconselhado colocar as informações em frente dos participantes antes de explicar o seu propósito, porque os participantes são curiosos!
- As personas criadas eram muito parecidas em todas as características descritas, o que pode ter facilitado e diminuído o tempo de resposta dos participantes.
- Esta parecença anulou um pouco a necessidade de explicação, que começou a ser apenas "este é igual ao outro, só muda isto …", tornando o workshop muito repetitivo, e pouco cativador. Isto levou a que os participantes colocassem bastantes vezes a frase "igual ao anterior" ao darem o feedback negativo.
- Ainda no mesmo tópico, as personas poderiam ter sido mais distintas entre elas, o que iria ajudar a obter mais informação sobre o perfil ideal.
- Como os participantes estavam muito focados nos mesmos grupos de características, podem não ter tido oportunidade de olhar tanto para os critérios de inclusão e exclusão, não tendo havido muito debate sobre isso.
- Talvez tivesse facilitado os participantes se cada tópico tivesse numerado, dessa forma não teriam demorado tanto tempo a copiar aquilo com que não concordavam.
- O tempo estimado para o workshop não foi todo ocupado o que alegrou os participantes.
- A presença de mais do que um representante por instituição permitiu que mais pessoas contribuíssem com as suas ideias.
- Na discussão aberta, todos os participantes concordaram que num estudo ideal todos os cargos deveriam ser pagos.
- Ainda nesta etapa foi revelado, pelos participantes, o perfil que achavam ideal para cada cargo: Entrevistador – Voluntário c/ algo a ganhar (estudante com uso de bicicleta sem pagamento); Team coach – Voluntário (pessoas reformadas, voluntários com tempo ou estudantes seniores); Supervisor – Voluntário c/ algo a ganhar (funcionário da CML ou estudante de mestrado com bolsa do IPL)

Podemos concluir que a realização do workshop foi muito importante e uma mais-valia para a tomada de decisões no estudo LISA. O feedback recolhido será posteriormente analisado e ajudará a definir as características que o estudo deve procurar para cada um dos cargos acima mencionados.

g. Identification of Cohort Study's challenges [35]

Problemas Identificados

Participantes:

- Dificuldade em angariar participantes (porta-a-porta, telefonemas ou carta)
- Necessidade de adaptar o método de follow-up (porta-a-porta, telefonemas ou carta)
- Essencial garantir a segurança dos participantes (evitar burlas e assaltos)
- Necessidade de manter a motivação no estudo.

Entrevistadores:

- Fundamental manter o compromisso com o estudo.
- Imprescindível a capacitação para a comunicação.
- Importante realizar formação constante dos entrevistadores.
- Necessidade de existência de um supervisor e alguém para backoffice.

Questionário:

- Fundamental decidir o local para realização (residência, ou deslocamento a unidades específicas)
- Necessidade de conhecer a forma de o realizar (lido pelo entrevistador ou participante, registado pelo entrevistador …)
- Útil perceber o formato a ser usado (digital, ou físico) ***convém ter plano B caso seja apenas digital.*
- Dificuldade na extensão do questionário.

A comunicação do estudo para a população:

- Essencial perceber os suportes e elementos gráficos a ser usados.
- Necessário perceber a zona em que será realizada a comunicação (rural, cidade, ...)
- Importante perceber os canais por onde passará a comunicação (hospitais, juntas de freguesia, centros de saúde...)

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;

[35] This document was a presentation, done on 07/02/22, intended to inform the cohort team about the interviews carried out and the challenges found. Since all the multidisciplinary team members are Portuguese, the document is presented in their native language.

Entrevistas População

Amostra Populacional: 8

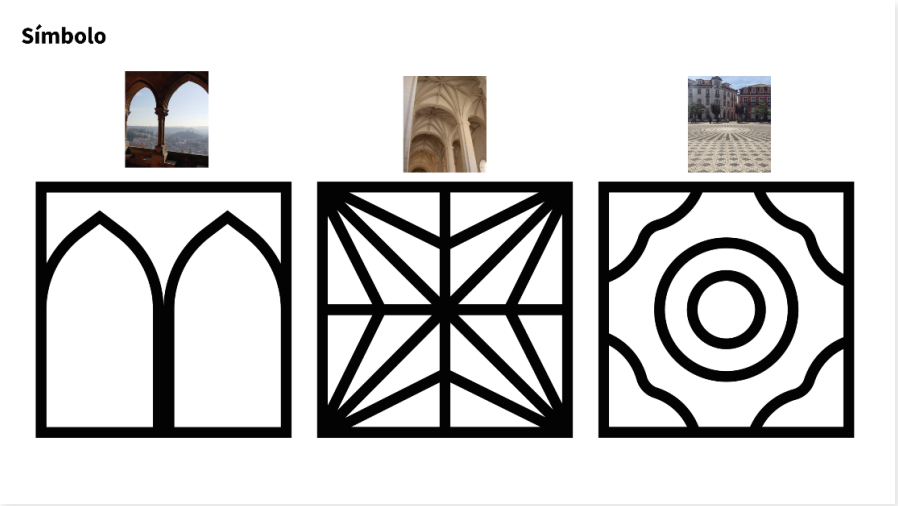
Género	Idade (anos)	Residência	Educação
Feminino	24	Cidade	Mestrado
Feminino	62	Rural	6º Ano
Feminino	43	Periferia	12º Ano
Feminino	55	Cidade	12º Ano
Feminino	78	Rural	4º Ano
Masculino	24	Periferia	TESP
Masculino	22	Rural	Licenciatura
Masculino	41	Cidade	Doutoramento

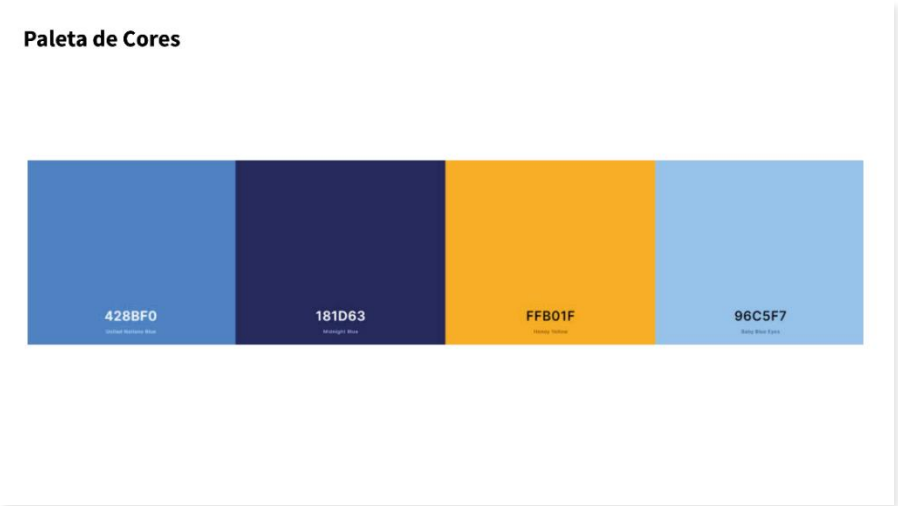
- Maior parte **desconhece o que é um estudo coorte**.
- Motivo de participação ganhar **mais conhecimentos em saúde**.
- Primeiro contacto por **carta ou email**.
- Publicitação em redes sociais, centros de saúde e **locais de maior afluência da região.**
- Horário de contacto ao **fim da tarde ou fins 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)

h. LISA's brand[36]





[36] This document was a presentation, done on 06/01/22, intended to inform the cohort study team about the brand designed. Since all the multidisciplinary team members are Portuguese, the document is presented in their native language.

Tipografia

Poppins	Source Sans Pro	Source Serif Pro
A B C D E F G H I J K L M N O P Q R S T U V W X Y Z a b c d e f g h i j k l m n o p q r s t u v w x y z 0 1 2 3 4 5 6 7 8 9 ! ? = ; . , " ( )	A B C D E F G H I J K L M N O P Q R S T U V W X Y Z a b c d e f g h i j k l m n o p q r s t u v w x y z 0 1 2 3 4 5 6 7 8 9 ! ? = ; . , " ( )	A B C D E F G H I J K L M N O P Q R S T U V W X Y Z a b c d e f g h i j k l m n o p q r s t u v w x y z 0 1 2 3 4 5 6 7 8 9 ! ? = ; . , " ( )

Proposta de marca

lisa

Proposta de Logótipo

Logótipo com Assinatura

i. LISA's work plan[37]

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

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)

[37] This document was a presentation, done on 14/02/22, made to share with the cohort study team the envisaged work plan. Since all the multidisciplinary team members are Portuguese, the document is presented in their native language.

Implementação

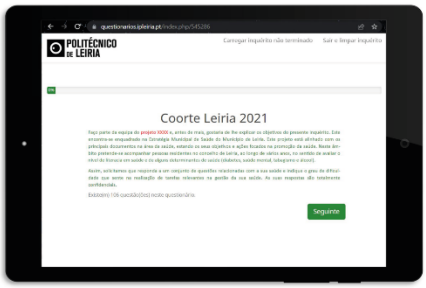
Instrumentos

Questionário

106 perguntas

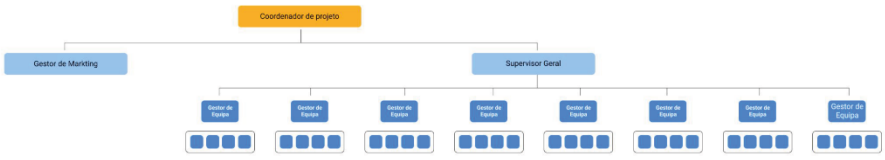
Inquéritos:

- 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.



Recursos Humanos

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



Recursos Materiais

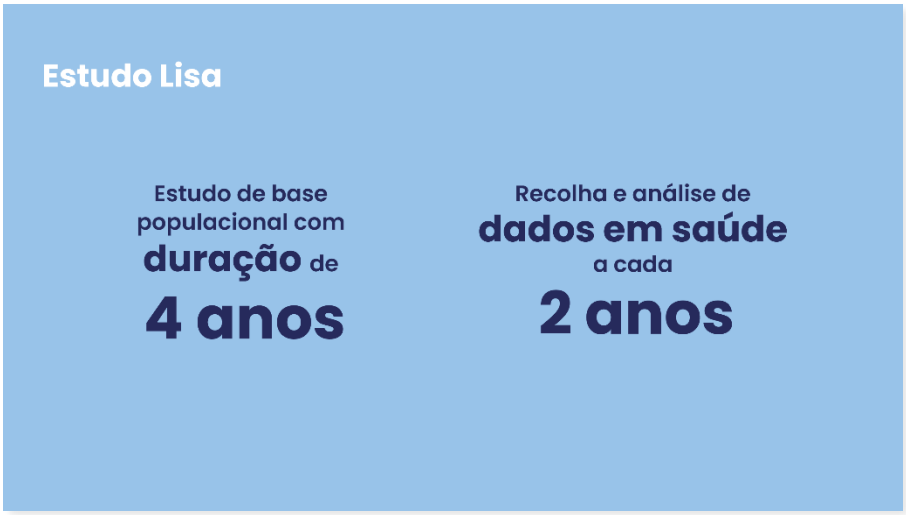
Comunicação do Projeto

- 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

j. LISA's official announcement in "Aldeia da Saúde"[38]



[38] This document was a presentation, done on 27/05/22, made to divulge LISA on "Aldeia da Saúde". Since all the multidisciplinary team members and the majority of the Leiria's population are Portuguese, the document is presented in their native language.

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!

Attachments

k. LISA's questionnaire[39]

D. Questionnaire

Durante o preenchimento do questionario apenas algumas perguntas podem ter ajuda no registo por parte do entrevistador. Estas ajudas vão estar descadas 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 advenha 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

8

[39] This questionnaire (part of the interviewers' handbook) is presented in Portuguese since it is based on a gathering of validated surveys. The text in red highlights the kind of help the interviewer can give to the interviewee.

- 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 triglicerídeos 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 crônica (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
- Cigarrilha de maço

- Cigarrilha 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 familia: 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 incluida 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 vómitos, 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. Informed consent for Interviews[40]

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 Leria

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.

[40] This document is presented in its original language (Portuguese), since the population sample interviewed was Portuguese.

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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, consequentemente, 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 parceira 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

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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 o 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.

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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 – 1º
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

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POLITÉCNICO DE LEIRIA | ciTechCare CENTER FOR INNOVATIVE CARE AND HEALTH TECHNOLOGY

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. Confirmo que recebi uma cópia assinada desde 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

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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

m. Distribution of Leiria's population[41]

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

Última atualização destes dados: 23 de novembro de 2022

[41] The document was exported from INE (National Statistical Office) initially with an age range from 0-100 years (here is a preview of one of the pages of the document). It was then analysed and organized to correspond to this cohort study age range. Since it was a document used by the multidisciplinary team it is being presented in its original language (Portuguese).

População residente (N.º) por Local de residência (à data dos Censos 2011), Sexo, Idade e Escalão de dimensão populacional; Decenal										
Sexo		H					M				
	Grupo etário	18-29 anos	30-44 anos	45-64 anos	+ 65 anos	Total	18-29 anos	30-44 anos	45-64 anos	+ 65 anos	Total
Local de residência (à data dos Censos 2011)	Leiria (concelho)	9367	14332	15963	9017	48679	9165	15208	17417	11719	53509
	Amor	325	552	643	361	1881	271	540	641	480	1932
	Arrabal	186	269	373	254	1082	157	258	385	296	1096
	Bajouca	164	232	242	156	794	149	200	249	188	786
	Bidoeira de Cima	147	251	266	205	869	126	267	280	252	925
	Caranguejeira	347	461	624	391	1823	324	493	649	489	1955
	Coimbrão	131	154	245	180	710	119	151	237	238	745
	Maceira	659	1038	1400	855	3952	637	1062	1437	1058	4194
	Milagres	244	312	450	212	1218	229	322	425	288	1264
	Regueira de Pontes	152	240	304	174	870	161	242	320	210	933
	Colmeias	220	280	435	326	1261	225	295	485	447	1452
	Memória	44	60	95	113	312	47	63	89	177	376
	Leiria	1277	1737	1524	996	5534	1210	1889	2083	1564	6746
	Pousos	694	1314	1159	495	3662	751	1382	1221	604	3958
	Barreira	337	541	468	243	1589	308	616	490	291	1705
	Cortes	242	290	456	232	1220	214	282	471	294	1261
	Marrazes	1648	2799	2582	1201	8230	1737	3196	3016	1516	9465
	Barosa	145	244	292	173	854	121	263	300	213	897
	Monte Real	203	319	381	212	1115	198	358	396	302	1254
	Carvide	161	278	389	262	1090	175	298	418	334	1225
	Monte Redondo	337	480	593	309	1719	355	471	622	375	1823
	Carreira	93	89	180	104	466	67	107	178	144	496
	Parceiros	345	667	525	253	1790	340	666	598	312	1916
	Azoia	167	216	338	177	898	171	239	347	215	972
	Santa Catarina da Serra	316	380	584	291	1571	310	413	586	398	1707
	Chainça	70	76	111	61	318	45	77	116	65	303
	Santa Eufémia	169	237	327	188	921	178	231	340	222	971
	Boa Vista	120	172	231	150	673	115	178	260	188	741
	Souto da Carpalhosa	281	401	513	317	1512	273	404	524	391	1592
	Ortigosa	143	243	233	126	745	152	245	254	168	819