

The Role of Design in Health Observational Studies

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Abstract

The specialization in "Design for Health and Well-being" has recently emerged in Portugal. This branch aims to bridge different fields, Design, Health, and Well-being. At the moment, we are working to identify what our role as designers is in the area, namely in a Cohort Study in Leiria, with 10 years duration. The present project arose from the cohort study's necessity to better reach the population. The study's objective is to monitor the population's health literacy level, through an inquiry-driven by a group of targeted selected interviewers. In this project, designers focused on User-Centered Design and Participatory Design supported by Service Design methodologies, through "Interviews", "Personas" and "Workshops" with "Service Blueprint", to grasp cohort studies' common concerns and the best way to tackle them. Understanding this new design approach was challenging. As part of a multidisciplinary team, we found that designers need to be involved in the project from the beginning and that design methodologies assist the organization of observational studies. Resulting, in this particular case, in the development of a set of communication guidelines for the study. In the future, our aim is to validate the role of a Designer specialized in Health and Well-being in this type of study, and further justify their attendance in the early stages of any project, since design methodologies can be applied to aid in multiple fields.

Keywords: Design for Health and Well-Being, Observational Studies, Cohort Study, Service Design, User-Centered Design, Participatory Design

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Introduction

Recently, a new design practice has been emerging in Portugal. It is called “Design for Health and Well-being” and until now, only two Portuguese institutions guarantee designers this specialization, one being a master's degree and the other a post-graduate degree. This type of design aims to bridge the fields of “Health and Well-being” and “Design”.

The World Health Organization (WHO) designates “Health and Well-being” as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (World Health Organization, n.d.). The knowledge of this definition aids in the description of what Design for Health and Well-being can be, but it’s also essential to understand what design is, and what can be done by applying it. According to Aakhus (2007) “design is an activity of transforming something given into something preferred through intervention and invention”. Therefore, a designer with this specialization can be described as someone that can use design methodologies, creative practices, and implementation of knowledge in order to aid organizations, institutions, companies, or services to improve health and well-being, change lifestyle behaviours or allow a better experience of a determined audience.

Throughout this paper, we will explain the role a designer for health and wellbeing can have in health observational studies, focusing on the work of two designers that were integrated into a multidisciplinary team of a health observational study.

Background

Observational studies belong to a category of analytic study designs, where the researcher monitors the connection between an exposure and an outcome, not intervening with actions (i.e. in experimental studies the researcher introduces a treatment to a specific group in order to understand its effects) (Song & Chung, 2010). This category of analytic studies can be divided into different types of studies: case-control studies, cross-sectional studies, and cohort studies (Song & Chung, 2010). In this specific case, the observational study is a prospective cohort study - a study that will monitor a group of people, from the present until the future, with some follow-ups to identify a specific outcome (Hulley et al., 2007).

The conception of this study began with public health doctors, from ACES Pinhal Litoral, noticing that the emergency systems of the county were overloaded because of system misuse. This brought up the question: “Do people go to the hospital emergency section with everyday issues because they don’t understand their needs?”. Adding to this, there was also a suspicion that the number of comorbidities and metabolic illnesses was a bit higher in the county of Leiria than in the surrounding areas (ACES Pinhal Litoral, 2019). These questions, made the City Hall of Leiria introduce the notion that the health and health literacy of the county of Leiria should be monitored to understand people’s decisions (Câmara Municipal de Leiria et al., 2021), leading to the cohort study LISA - Longitudinal Study of Health Literacy in the County of Leiria.

As the name says, LISA is a cohort study that aims to understand the cause of these issues, by monitoring the health literacy levels of the adult population of Leiria’s county. Adding to this, it also proposes to compare them with the lifestyle habits, drinking and smoking behaviours, predisposition to metabolic diseases, and mental health conditions of the same target population. Such monitoring is done via a questionnaire, delivered by previously

selected interviewers, who will randomly knock on the door of the population living in the county of Leiria.

Organizing the Lisa Cohort Study is a group of institutions formed by two research centres of Polytechnic of Leiria (ciTechCare - Center for Innovative Care and Health Technology, and LIDA - Research Laboratory in Design and Arts), ACES Pinhal litoral (the headquarters of healthcare facilities in the region), the City Hall of Leiria, and the Leiria Hospital Centre. This cooperation is reflected in a multidisciplinary team, composed of Researchers, Designers, Public Health Doctors, City Hall Representatives, Nurses, etc., that intend to keep the study running for ten years, doing a follow-up every two years.

Designers' Role in LISA

The journey to find the designers' role in this study began in meetings held with the stakeholder team, during these meetings some preconceptions held by the stakeholders on what a designer could do were brought to light, but by explaining what we as designers for health and well-being can do, and how our proposed design process could help expedite the study's development, those preconceptions were cleared, opening the road for the definition of our role in the study.

The purpose of being in the LISA cohort study's team ultimately is the definition of the communication model and the identification of adequate and suitable interviewers to carry out the study's ambitions. Our role is also to use design methodologies, (which will be further explained in the next section) to aid the structuration of the LISA Cohort Study, and improve the communication between the stakeholders.

Design Process

The communication strategy of LISA was divided into two topics, what information is displayed and how it's presented. What information is displayed has to do with the study's branding, its objectives and structure, this is because if the study has a recognizable brand before it launches the population will be more receptive to it. How information is presented relates to the places where it's available, as in the website, the printable (i.e. flyers and posters) and other digital supports (i.e. social media), the expected outcome of this process is the increased trust of the population.

To aid in the development of this study the design team made use of Service Design, User-Centered Design and Participatory Design. These design approaches have the ability to create a connection to the user and their needs (Stickdorn et al., 2018). The methods and methodologies used in the design process belong to either one or both of the chosen design approaches.

Interviews were the chosen method to kickstart this design process. This method allows the interviewees to feel comfortable while talking about their experiences and needs (Martin & Hanington, 2012; Seidman, 2006). There were two goals in using this methodology, to understand what has been done in other cohort studies in Portugal, by interviewing experts, and to understand the expectations and preconceptions the population of Leiria's county might have had concerning the LISA study. For this, two sets of interviews were planned, the first with cohort experts and the second with a sample of the target population, the elements of this sample were chosen by their ability to represent different socio-economic

backgrounds. By the end of these interviews, we were able to compile a list of identified challenges.

Expert	Affiliation
Sara Dias	School of Health Sciences, Polytechnic of Leiria, Leiria, Portugal Center for Innovative Care and Health Technology (ciTechCare), Polytechnic of Leiria, Leiria, Portugal
Carla Lopes	Epidemiology Research Unit (EPIUnit), Medical School of University of Porto
Helena Canhão	EpiDoC Unit, CEDOC - Center for Chronic Disease Studies NOVA Medical School / Faculty of Medical Sciences CHRC Comprehensive Health Research Center
Ana Rodrigues	EpiDoC Unit, CEDOC - Center for Chronic Disease Studies NOVA Medical School / Faculty of Medical Sciences CHRC Comprehensive Health Research Center

Table 1. List of Interviewed Experts and their affiliations

Gender	Age (years)	Geographic Placement	Education Level
Female	24	City	Masters Degree
Female	62	Village	6th Grade
Female	43	Outskirts	12th Grade
Female	55	City	12th Grade
Female	78	Village	4th Grade
Male	24	Outskirts	TESP (professional higher technical courses)
Male	22	Village	Bachelor's Degree
Male	41	City	PhD

Table 2. List of the sample of the population interviewed.

Following the interviews, the personas (Miaskiewicz & Kozar, 2011) were developed. This method was chosen because of the need to create profile models that could be used when hiring the LISA's study interviewers. By using the information gathered in the interviews it was possible to create more accurate profile models for the personas (Ferreira et al., 2015) as well as an outline of the physical appearance the interviewers should have. In total nine personas were developed, accounting for their place in the team structure - supervisor, team coach, or interviewer - and their possible motivations - voluntary, voluntary with something to gain (i.e. a benefit other than monetary gain) or paid worker. These nine personality templates went through a validation process during the Red and Green Feedback workshop.

During this process, the stakeholders took into consideration the responsibilities and demands of each rank and chose the personas that would benefit the study.

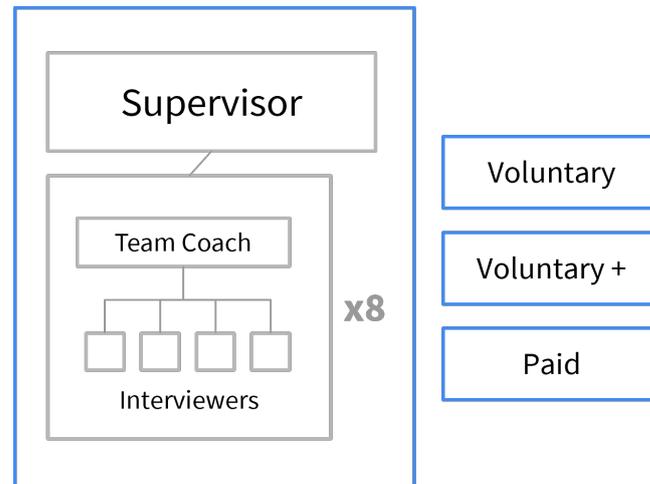


Figure 1: Field team structure and possible persona motivations

The last methods to be used were the Service Blueprint and Red and Green Feedback workshops. Both were held on the same day, in a face-to-face format, in ciTechCare research centre. The participants were chosen from among the stakeholders belonging to the institutions organizing the study - doctors, researchers, and representatives of the municipal council. Belonging to the User-Centered Design and Participatory Design methodology, these workshops will allow a horizontal interaction between participants from diverse fields, with no perception of their hierarchical levels within the institutions (Postma et al., 2012). These approaches will also aid in the making of a strategic plan that will address the need to adapt communication with the LISA population (Kumar, 2013).

The first one to be conducted was the Service Blueprint, where two stakeholders from each institution were present. The objective was to foresee the actions of the population, actions of the interviewers, the interactions between them, and also the actions of the staff and the supports, which usually are invisible to the population (Design Council & Technology Strategy Board: Driving Innovation, 2015). This workshop was divided into two sessions of one hour, and twelve stages that were related to the phase of the study. The First Session had four stages - Interviewer Recruitment, Interviewer Training, Itinerary, Communication of the Study. The Second Session was formed into eight stages, where six belong to the implementation of the questionnaire - First Contact, Study Explanation, Document Delivery and Explanation, Questionnaire, End of the Questionnaire, Time for Rescheduling-, and two of the stages were related to the End of the 1st Phase of the study, and the other was what will be needed for the Next Phase of LISA. The participants had in their possession post-its, with each color corresponding to a group: Actions of the Population, Actions of the Interviewers, Touchpoints, Action of the Staff, and Materials. In each stage, the participants were able to discuss and write their ideas for ten minutes, and then the facilitator would ask for the notes, putting them on the board. The process was repeated throughout the rest of the stages until it was possible to visualize the majority of the actions that will possibly occur during the Implementation of the LISA cohort Study. The workshop last step was a moment of discussion between the participants and designers regarding the bigger picture of LISA's Structure.



Figure 2: Board of the 2nd Session of the Service Blueprint

Red and Green Feedback is an approach that is connected to the Service Design methodology and allows the interaction between the stakeholders and designers (Stickdorn et al., 2018). The main objective of this method is the validation of the personas, leading to the ideal profile for the interviewers, team coaches, and supervisors. In this workshop, only five of the six previous participants were available.

This workshop had one session with a duration of one hour. There the moderator would present one of the personas and the stakeholders could write on post-its of two colours. The colour red would mean something needed to be improved. The colour green would mean that something was right and that they agreed with it. Participants had five minutes to write their ideas in silence, and then the moderator would collect the post-its and paste them on the board. In the end, there was a moment of discussion where the participants could look at the board and decide if something essential was missing. The feedback collected helped define the characteristics that the study should look for in each of the available field team positions.

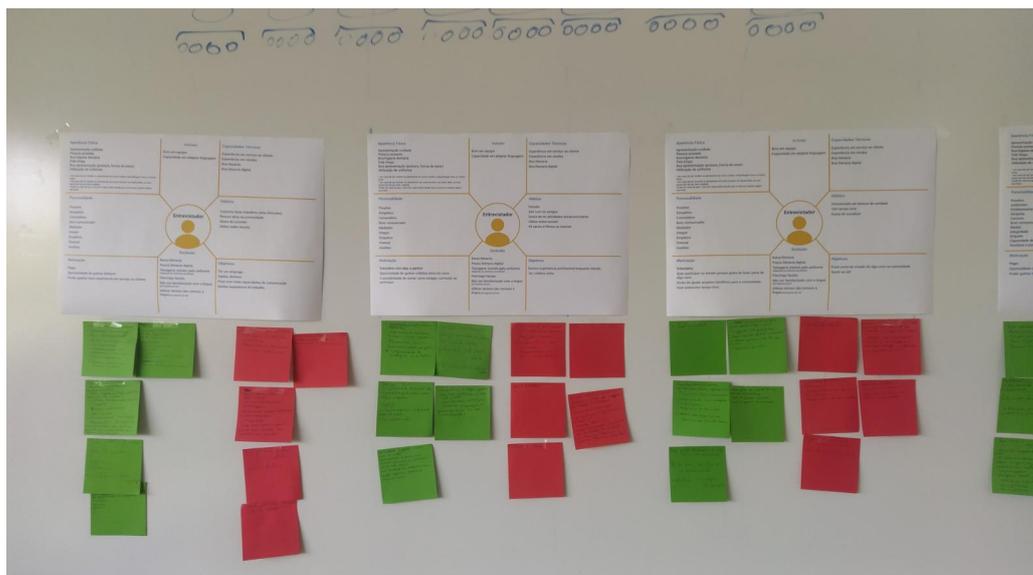


Figure 3: Red and Green Feedback workshop with personas.

Outcomes

Although the design team's work is not yet concluded, by following the charted design process the team was able to obtain some outcomes, they come from the used methodologies and are elements that helped the designers steer the project closer to its objectives.

One of the outcomes of the design process, from the used methodologies, is a list of identified challenges. This list was compiled with the information provided in the interviews with the experts and the population, in it are common cohort issues, as described by the experts, and possible barriers identified by the population. Some of these identified challenges are as follows:

- Getting a sample large and diverse enough to be representative of the whole population is one of the most demanding tasks.
- From one interval of the study to the next, it's common to have a large drop in participants, so it's important to keep both the team and the participants motivated.
- The team members must be capacitated so they can adapt to different kinds of participants and maintain the study's efficiency.
- The communication and advertisement must be adequate to the target population, taking into consideration the possible socio-economic differences, so the message of the study can be properly conveyed.
- The study and its purpose must be attractive to the participants.
- The population may be suspicious of the interviewers at first, good identification is key.
- The duration of the interview shouldn't go past the 30-minute mark, or it may become cumbersome.

By having this list the team was able to focus on adapting pre-existing study assets to better comply with the solutions to the identified challenges and to develop the design process in the way that would most benefit the study.

Another outcome of the employed methodologies is the "Structure of the LISA Cohort Study". This document results from the analysis of the collected feedback in one of the aforementioned workshops, the Service Blueprint. In it, is possible to find all the stakeholders' "assumptions" regarding the scenarios they will encounter during the implementation of the study, from the recruitment of interviewers to the preparation for the next follow-up.

And lastly, the final outcome is the developed personas, validated through a Red and Green Feedback workshop. These personas were developed so that the stakeholders could have a template of the kind of person they should look for when hiring interviewers. The result of their development process was the final four chosen personas, the voluntary with something to gain interviewer, the voluntary team coach, and finally, it was decided that the supervisor should be a voluntary with something to gain connected to one of the involved institutions or a paid worker.

Final Considerations

Regarding the communication process, no conclusions can be drawn as of yet, since the LISA Cohort Study is in its preparatory phase. The outcomes of this process can only be identified

after two follow-up phases of this study. Even though the ideal personas were identified, the team selection process has not yet started. It is also crucial to register that the workshops were implemented only with stakeholders because the study's population will be randomized. Considering this research it is possible to see that the role of a designer for health and wellbeing can be highly flexible, as a designer has various skills and knowledge that can be employed in this type of observational studies. However, it is crucial to show how the designers can in fact impact the preparatory stages of a study, by using their design competences and methodologies. It should also be noted that their function can be influenced by the team in which the designer is included, and the preconceived notions that these people have about the designer's work.

In the future, we intend to have a better understanding of how this type of design can be integrated into any stage of a variety of studies, not only cohort studies or observational studies, validating the specialization in the process.

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