

MESG

MESTRADO EM ENGENHARIA DE SERVIÇOS E GESTÃO

Designing out stigma in an online-based sexual health promotion programme

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“Of all men's miseries the bitterest is this: to know so much and to have control over nothing.” - Herodotus

Abstract

Stigma remains very present when addressing subjects of sexuality and general vulnerability, not only when researching in stigma inducing themes but also in more general and mundane activities, such as the daily life of an older person that requires some type of assistance in any of their tasks. It is important to explore the dimensions of this said stigma and see how it takes place in technology related fields, such as Human-Computer Interaction (HCI) and Design. It is still complicated to study stigmatizing issues due to outdated assumptions and practices.

When it comes to sexual health this subject is even more notorious because it brings forth some inaccuracies perpetuated by society that carry themselves to several other areas of knowledge. Due to their pervasiveness in everyday life an easy access, digital technologies, namely mobile devices, show promise in being a good instrument to address sexual health safely and allowing the users to be in control. But the main challenge remains: how can researchers bring forth these users to understand their needs and pains without arising stigmatic concerns and people's desire to hide their vulnerabilities especially concerning sexual health?

This work aims to identify barriers faced by HCI and Design researchers, while identifying strategies to overcome current challenges in engaging older adults with vulnerabilities in research around stigmatizing topics.

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List of abbreviations

HCI	Human-Computer Interaction
TA	Thematic Analysis
STD	Sexually Transmitted Disease

1. Introduction

Developed societies in the Western world have been seeing an increase in average life expectancy alongside continuous improvements being made in the medical care industry. This allows for the noticeable surfacing of chronic illnesses among older adults. These adults are still interested in sexuality but because of these diseases, this part of their lives might be negatively affected (Traeen et al., 2016). Sexual health is a key dimension of general global health, and it bears a close relationship to physical and psychological health, which in turn influences general feelings of well-being and quality of life (WHO, 2006).

Designing technological solutions for this substratum of the population has been surrounded by some shortcomings and mistakes, with designers often failing to understand the sense of identity, technology acceptance and the context where elderly users carry their daily lives. This leads to oversimplification of user's complex needs towards technology, consequently, applying stigma-inducing features in their designs, which may antagonize the user's identity when using the products (Li et al., 2020). Product related stigma is perpetuated because often users are expected to just accept the products that enhance their daily lives and disregard all the stigma and embarrassment that come with it. Because of this, some choices are made in design that not only emphasize user's disability but completely disregard other aspects such as aesthetics and general product appearance which even further increases the already existing social stigma (Vaes, 2019). Furthermore, researchers that do not belong to the stigmatized groups and conduct their research among stigmatized subjects tend to base their work around theories that do not consider the lived experience of the people being studied (Link & Phelan, 2001).

Defining methods to use in HCI and interaction design for erotic life is challenging, because since it is such an intimate and private topic, it is very difficult to be observed by outsiders (Bertelsen & Petersen, 2007). In this research, we have proposed to address this gap by gathering data from professionals that are exposed to these problems in their work and understand the strategies they use to deal with them so that information can later be tested with possible users.

This dissertation is divided into three sections. It begins by reviewing literature, so it is possible to situate the problem and understand the variety of topics and how they interact with each other, therefore establishing a baseline. Following the literature review comes the methodology section in which research methods are explored to define which are the most suited to apply to the current subject followed by the actual result of this exploration which will be used to conduct the research, namely Design Studies and Qualitative research, which took advantage of data collection methods such as in-depth interviews and focus groups, the gathered data from the interviews was then analyzed using Thematic Analysis.

Finally, there is a conclusion section that closes the report by explaining the results of the exploration and also to display some of the lessons learned during the course of the development of the present work.

1.1. Research Questions

The aim of this dissertation is to improve the way research is conducted with highly stigmatized individuals in the fields of design and human-computer interaction. This dissertation took a human-centered approach to guarantee that the people involved have a voice and their concerns are heard and taken into account. Specifically, we formulated the following research questions:

- What are barriers that may hinder the process of researching with stigmatized individuals?
- How can research in HCI and Interaction Design be conducted in order overcome these barriers and cater to individuals with highly stigmatized conditions?

1.2. Study and Project Development at Fraunhofer

This Project was conducted at Fraunhofer AICOS, as part of a major company project that is being developed internationally with various countries from the European Union, the name of the project is ANATHEMA and it aims to provide a mobile online-base sexual health programme to help users with colorectal cancer to maintain an active and healthy sexual life.

Fraunhofer Portugal AICOS, the organization responsible for the present research, is a private non-profit research center, and part of the largest applied research organization in Europe. It is composed of three major research departments: Cyber-physical Systems, Artificial Intelligence and Human-Centred Design, the latter of which is where this research was held.

2. Literature Review

In order to better understand the problem framing previously defined a literature review was made regarding four different major topics, each of them addressed for the following reasons:

Design Emotion: Understand the various dimensions that influence emotion towards design, with a focus on feelings of stigma and how they affect product use and adoption. Some information is also needed regarding design choices that elicit these feelings of stigma.

Stigma: Define what stigma is and how it affects the daily lives of people living with stigma inducing conditions, from challenges people face to consequences in accepting solutions that improve quality of life.

Inclusive Design: Characterize inclusive design and the changes it brought to the traditional design approach, also review the advantages, and challenges it faces when designing for people with stigmatized conditions.

HCI and Sexual Health: Review what HCI is and how research is currently being conducted. Some information regarding the various stages of HCI was gathered to better understand how it contributes to the intimate lives of users and how it deals with difficult to address topics.

Service Design in Healthcare: The goal for this section is to gather some Service Design methods and concepts that can help not only conduct the research paired with design but also to provide some service design feedback for the service that serves as a baseline for the present research.

2.1. Design Emotion

There are a few components that influence emotions towards product design, such as:

Product Experience can be defined as “the entire set of affects that is elicited by the interaction between a user and a product, including the degree to which all our senses are gratified (aesthetic experience), the meanings we attach to the product (experience of meaning) and the feelings and emotions that are elicited (emotional experience)” (Hekkert, 2006, p3). Furthermore, Desmet & Hekkert (2007) distinguish three different levels of product experience which are: aesthetic pleasure, attribution of meaning and emotional response. Regarding aesthetic pleasure, the product’s capacity to delight one or more of our sensory modalities is considered. Attribution of meaning is made through cognitive processes like interpretation, memory retrieval and associations, which allows people to recognize metaphors, allocate a personality or expressive characteristics and evaluate the personal significance of products. Emotional response refers to the emotions that are uncovered by the use of a certain objects, this emotions can range from love, fear and disgust, to name some possibilities. One clear example of this is when someone hears their phone ringing, depending on what they associate with that ring, the same event can elicit different emotional responses from different users.

There are some design factors that bring forth the feelings of stigma, they explain the causes of stigma in design from four perspectives, namely, lack of aesthetic appeal, accentuated social signifiers, poor affordance, and neglect of privacy. The study conducted by Li et al. (2020) inferred that older adults have some usual standards regarding aesthetics and when this factor is neglected, they can associate some specific negative characteristics from the product to themselves, which can potentially lead to limited use or even abandonment. This factor encompasses different aspects of aesthetics, such as color, material quality, form and general design that is deemed socially appropriate. Regarding social signifiers, they refer to characteristics in product design that make outsiders aware of negative attributes of the user.

These can refer to obvious instructions or some general characteristics often attributed to older users, such as big buttons and large devices. Affordance is something designers use to map products so they can be used, in this case for older adults, when there is poor affordance or the mapping is not adequate for use, it can possibly bring forth negative feelings for the users and thus low acceptance for the products. Finally, taking into account privacy concerns is critical for product acceptance, with older adults often considering living their daily lives free from obstruction more important than their health concerns, they often reject the innovative options that offer some new functionalities that undermine their privacy such as tracking and general device monitoring (Li et al., 2020).

Another aspect to be considered is the usage of related situational cues, since the situation where devices are used is very important in the eyes of the older population as seen by Chen & Chan (2013).

Several concerns regarding usage affect older adults, such as the effect the usage will have on the perception of other people and how they attract their attention. The collective representations are referred to by older adults to make situational considerations of product use and access these considerations in order to verify if it poses an identity threat in use (Li et al., 2020).

There are some characteristics that will help the designs be accepted and generate positive emotions towards the products. Namely, some suggestions were made for design by Schifferstein & Zwartkruis-Pelgrim (2008) that refer to the importance of bringing enjoyment and associations with people and events in the user's lives to help create an emotional bond with the product. This bond can also be improved by allowing the users to personalize their products, mainly regarding the visual aspects of the products since it will help support the user's identity and therefore depend on the attachment with the product (Mugge et al., 2009).

2.2. Stigma

There are four types of stigma, public stigma which is considered to be at the centre of all of them, which refers to the consensual notion that an attribute is frowned upon, there is the self-stigma that reflects the social and psychological consequences of possessing a stigma inducing condition, the third one is stigma by association, which are the reactions and feelings of people that have a relationship with the stigmatized person and finally the fourth type is the structural-stigma that concerns the continuation of the status of stigma throughout the society's institutions (Bos et al., 2013; Roozen et al., 2020).

There's a misconception that stigma is related to one's own functional limitations of one's impairment, but actually the source of feelings of stigma come from the societal and social responses towards disability (Goffman, 2009). This is also clear when talking about the collective representations of older adults, which refer to the common cultural assumptions and stereotypes regarding older adults that society has, which affect older adults in different dimensions of their lives, such as how they perceive aging, how they dress and so on. This collective representation is also exacerbated by the frequent negative stories surrounding older adults, such as loud behavior and disregard for road safety for example. (Li et al., 2020).

A concerning effect of stigma is the difficulties it creates when users are considering treatment of some medical condition, as suggested by Shen & Wellman (2019). Some medical treatment that is perceived as valuable and helpful for alleviating pain and improve the patient's life, like palliative care, faces a great barrier because it's negatively perceived and surrounded by stigma, which makes patients and their families less likely to use it despite its benefits.

2.3. Inclusive Design

Inclusive design challenges prior approaches to design that focused on designing for the disabled and elderly people as a specific set of the population to one that considers this subset within the total mainstream society. There are two premises underlying this approach: 1) people are very different from each other, from their abilities, both physical and mental, to their capabilities along their lives, which may change due to temporary conditions such as pregnancies for example, and 2) disability arises from the interactions the user has with the environment and not necessarily due to lack of capability or health concerns. This also proposes an interesting business case for inclusive design, where considering the needs of older and less able people which constitute a significant part of the population with sizeable spending power, even more if we take into account the previously mentioned temporary disabilities, might lead to acquiring a broad market and brand power (John Clarkson & Coleman, 2015).

Very often we see Inclusive Design being associated with the concept of accessibility, but although accessibility is in fact part of Inclusive Design they are two different things, with accessibility focusing on the rules designers follow that focus on motor, sensory and cognitive inabilities, Inclusive design is a possible approach to designing (Clarkson et al., 2013).

There are some other questions that surround inclusive design, such as fairness, since it is impossible to design for every single person that exists, it is very difficult for designers to decide which ones to address (Bianchin & Heylighen, 2017). This specific concern is often counteracted by using a user centric approach that aims to design for the average user, this also prioritizes the needs of some individuals instead of others and by claiming the idea of an average human being, it is inevitable to exclude a vast portion of the population that does not fit into this idea of average (Patrick & Hollenbeck, 2021).

The above-mentioned approaches such as user-centeredness, although being very useful and invaluable for mainstream design, fall short when they are applied to users who are older or disabled. In this specific field the movements such as the inclusive design incentivize designers to bring older people and disabled people into the design briefs, but this also provides designers with a problem, which is the traditional focus on producing prototypes and then see how they can include older and disabled people. This can cause a design to be accessible but not actually usable (Newell et al., 2011).

2.4. HCI and Sexual Health

Human-Computer Interaction (HCI) studies how human beings interact with digital technology. As a scientific field, it has been theorized as having gone through three “waves”. First Wave HCI, focuses on the ergonomics and the simple interaction disruptions between human and machine, therefore addresses specific problems and uses very simple metrics. The second wave brings into consideration the cognitive side, namely the way the mind processes information given by the machine. This changes the perception of users as simplistic beings to people that have a set of skills and work experience (Duarte & Baranauskas, 2016).

Third Wave HCI, expands the context and types of developed applications focused on work from the previous Second wave, by spreading technology to the user’s homes, private lives and cultural setting (Bødker, 2006). This shift brought forth some new challenges, namely, how could someone study and design for users that weren’t part of any specific group, in varying circumstances, with no clear tasks planned and for individuals inserted in very different cultures. By the year 2000 the HCI field became more focused on a broader range of issues, such as meaning, emotion, culture, complexity and life experience (Fallman, 2011).

With this newfound interest in designing for fun, HCI can insert itself in designing for the erotic life, by bringing better ways to do so other than the medically charged approaches to this topic often used in the western world. Other than this, technology can serve as an enabler of intimate and sexual experiences and therefore impact the sexual life of users. With this in mind, and considering that technology is becoming omnipresent, it is key that HCI takes into account intimacy and sexuality in order to avoid damaging the private life of users (Bertelsen & Petersen, 2007). Although these discussions of sexuality are being brought to HCI, it is still valuable to understand that sexuality in HCI is discussed only when thinking about technology, which means that the sexual themes of discussion must be exposed in technological terms (Kannabiran et al., 2011).

2.5. Service Design for Health

Before addressing the use Service Design might have when addressing health and societal change, it is important to clarify what Service Design is and what it aims to do in general. Service Design takes a human-centered approach that has at its core the customer and the perceived quality of the service encounter by that customer, but, although the core is user-centric it also considers in an integrated way other decisions such as strategic, system, process and touch-point design. By using this approach alongside a systematic and iterative process it is able to create services that are useful, useable, desirable, efficient and effective (Saco & Goncalves, 2008).

Like mentioned previously, Service Design also has some uses when working with health-related topics since it can be a great contributor for health care transformation because it provides a human-centred, holistic and iterative approach to the development of new services, by comprehending human experience, it can help transform this understanding into the services being created. By also using participatory design approaches it can deeply engage with users in transformation processes. Pairing these characteristics with its disruptive approach to perceive the future, it is a great tool to help innovate among healthcare systems and shift societal norms (Patrício et al., 2020), not only that but it can also act as a big driver of institutional change, which is something that is key to carry healthcare innovation forward, these systems often carry the weight of various societal norms and structures, therefore it is imperative that this operational shift happens (Koskela-Huotari et al., 2021).

Picking up on the before-mentioned possibilities of using service Design, it is important to know that it can be a driver of societal changes, especially since it boosts reflexivity which is key to avoid reproducing social structures mindlessly, people need to be able to reflect, this means that they need to be aware of the social structures that exist in the places they are operating. A definition of service design was proposed by Vink et al. (2021) that suggests that service design is intentionally shaping the mentioned social structures to allow for value cocreation forms to rise, they are very keen on using the before-mentioned reflexivity, to guarantee that people can actually create change and alter the structures that surround them instead of only reproducing the same structures that already exist, therefore Service Design is more than just a stage in creating a new service, it is actually a disrupting force for the social systems that are currently in place.

Six modes of leveraging this reflexivity were proposed by (Vink & Koskela-Huotari, 2022) as well as the method of service design that is capable of supporting that said leverage, namely they are:

- Temporal, reflexivity is supported by analyzing the history of institutions and what they do and represent, also it is suggested that the said social structures are constituted through the progress of history.
- Material, knowledge of social structures gathered through the interaction with artifacts that prompt the sought reflexivity.
- Corporeal, information gathered through the bodily sensations of the individuals, these sensations prompt the individuals to challenge the social structures and the perceptions and interactions with the world.

- Relational, the interpretation of social structures by the interactions with other individuals.
- Cultural, analysis of the social structures by the behaviors of groups of people and the common customs in the said society.
- Cognitive, perceptions of the social structures by analyzing the inner thoughts of individuals.

3. Problem Characterization

Fraunhofer AICOS has been developing a mobile-based sexual health education programme for older adults, under the name of Anathema, that aims to increase these user's access to sexual health support and increase the usage of technology by these users by providing a fulfilling user experience catered to them. If successful, the smartphone application is to be commercialized, in two different ways, first in a modular form inserted in an already existing psychology platform and as a standalone app.



Figure 1 - Visual Content from ANATHEMA

Based on the literature reviewed in the previous chapter, it was clear that there is a lot of space left to explore in designing and researching stigmatized populations such as older adults, with often falling on utilizing techniques that do not work when dealing with these topics, for instance the utilization of archetypes and personas while designing for intimacy and sexual health which is a theme that requires a very high degree of personalization leads to failures in design and in understanding the population for each the design is being done. Not only that, but the lack of understanding researchers have of these populations severely hinders the whole process of creating new products and services, from ideation to delivery, even in some cases technology required for survival and wellbeing is being rejected because the feelings and choices of the population are not being taken into consideration.

To counteract this problem, this research used Service Design and Qualitative Research methods to gather advice and good practices from current working professionals in the area and later test some of those methods together with users in order to review and give some feedback about how they do when addressing sensitive topics, namely, sexual health.

This still is a very difficult area to approach, since it faces different barriers at the different stages of research. These barriers come from different places, some of them are barriers that come from the users themselves, whether they are mental or physical barriers. The end goal of the research is to improve the way research is conducted around stigmatizing topics by building upon the existing body of knowledge by testing some of the methodologies and discovering new ones that can provide good results.

4. Methodology

In order to select a work methodology for the development of this work, it was imperative to consider what was the goal of the said work, therefore we should refer to the questions that we want to see answered (Fallman, 2008). This project used as a framework for the methodologies to be used, The Interaction Design Research Triangle of Design practice, which is a model that is being developed by the Umeå Institute of Design in Sweden, the triangle is represented by the next image.

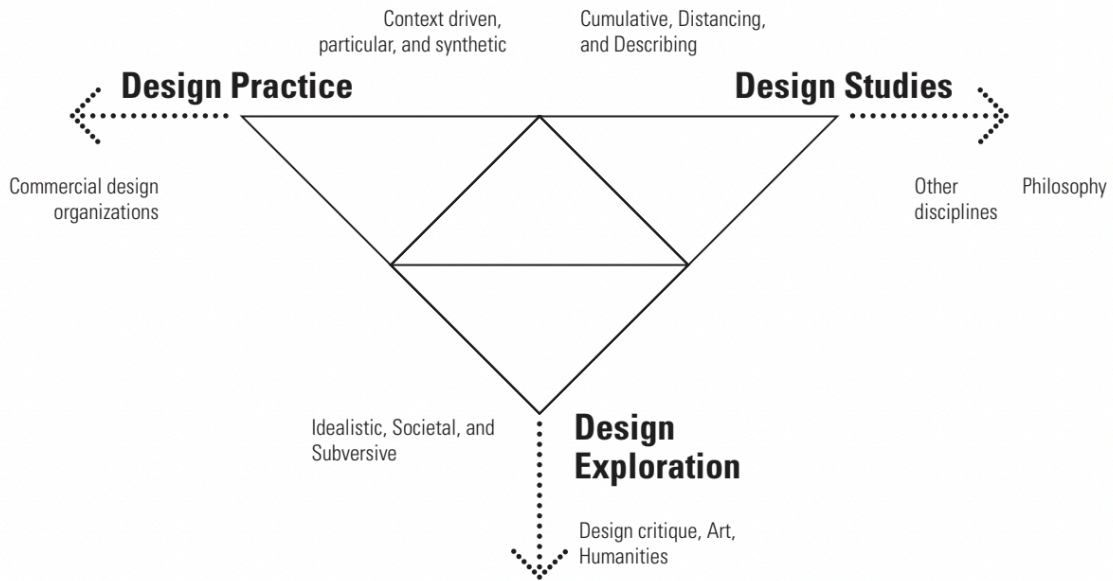


Figure 2 - The Interaction Design Research Triangle of Design practice (Fallman, 2008)

For this work, the route chosen was the route of Design Studies, which is similar to traditional academic disciplines and aims to build upon the already existing body of knowledge. This goal forces the researcher to take part in a sizeable amount of analytical work and to contribute, in this case, to the design methodologies that are used. This methodology is a good pair to use with qualitative work given that is very open to work with other disciplines, for example the social sciences, given the sensitive topics that will be addressed during this work, it is important to be open to knowledge of other areas of expertise. This methodology also has a key characteristic which is that it aims to understand and thus evolve the body of knowledge (Fallman, 2008).

The development of knowledge in the fields associated with stigma require methodologies that fit with the humane sensitivity to the topics, therefore, qualitative research proves the best fit, since it understands research queries as humanistic and, other than that, is often used to understand personal considerations of people, such as their beliefs, experiences, attitudes, behavior, and interactions, by providing more user involvement, by granting subjects a voice and an active role in the study where individuals can expose their concerns and benefits regarding the study. This methodology also allows the researcher to create a relationship with the subject (Pathak et al., 2013). Qualitative research is focused on subjective meanings and there is a consensus regarding some of its aims, such as understanding human experience, using interviews and focus groups as a means to understand people's thoughts and creating empathetic skills among researchers in order to achieve these aims (Silverman, 2020).

The research required several methods to gather the data from the professionals in the area and also from the possible users of the service that serves as a baseline for this work. Interviews are one of the most widely used strategies for collecting qualitative data. Given the subject of this work, which relates heavily to health, in-depth interviews were used since they are extensively used by health care researchers (DiCicco-Bloom & Crabtree, 2006). It is very important to formally analyze the data gathered by interviews, since it serves as a baseline for all the further research done in this work. The chosen method of analysis was Thematic Analysis, which is used to identify, organize and collect insight and then aggregate them into themes across data sets. It enables the researcher to better analyze experiences and attributed meanings from the providers of data. The main goal is to make sense of the way the topic being studied is talked or written about and identify the common ground (Joffe, 2012). Since good qualitative work searches for complicated interpretations for phenomena occurred in social settings, it requires a change from taking measures to understanding and from statistics to interpretations (Braun & Clarke, 2012).

This research also used Focus groups to test the methodologies that will be gathered through the interview process, this method has been defined as “a research technique that collects data through group interaction on a topic determined by the researcher” (Morgan, 1996, p130). This is a broad definition but it gives three key pieces of information: it clearly states that is a means to collect data, it indicates that the source of the data is the group in question and finally that the researcher has an active role in the discussion (Morgan, 1996). This method has been used in several relevant studies in the past such as Almeida et al. (2016), Cook et al. (2022), Schulte et al. (2021) or Wood et al. (2017).

The last data collection method used was observation, since usually people have a tough time explaining what they do and how they act. It is very difficult for a designer to get a full sense of the behavior through methods that require user input such as interviews and questionnaires. Observation can help gather details about how people actually behave and the nuances of their interactions, also it is a great way to be immersed in the context of interaction (Sharp et al., 2019).

4.1. Methodology application

The methodology used for this dissertation followed a logical order of events in the sense that the previous even always contributed to the development of the next one. Starting with interviews to gather information from which the methodologies were discovered, to the development of focus groups which used the information from the previous section to define methodologies to be tested. After the focus groups the results were used to developed a new workshop that would be observed to evaluate how those iterated methodologies would work when applied in the real world.

The following graphic depicts the work plan for the data gathering and analysis used for the development of this work.

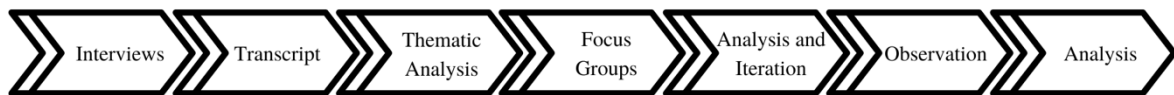


Figure 3 - Work plan for methodology application in data gathering and analysis

4.1.1. Design Studies

This research began by understanding the current body of knowledge available to Design Researchers in the field of stigmatizing topics, this was done by conducting the preliminary literature review and the complemented by interviewing professionals that are actively working in the area, by doing this it was possible to develop a good baseline knowledge from each to build this research.

With the information established, it was later tested several times through different methods, the information was testes using focus groups and one workshop that was observed so it was possible to evaluate its effectiveness and find new previously unknown information.

With the analysis of this information as a whole, it was possible to create some consensus of information as well as add new one to contribute to the ever-growing body of knowledge present in the field of Design, especially Design related with stigmatizing conditions.

4.1.2. Sample Design

The starting point was the sample design for the various stages that required participants to provide with insights. Given that the main goal of the different stages was different and therefore required different inputs, sample designs were customized for specific stages.

Starting with interviews, the sample was defined by designers or design researchers that had experience working around stigmatizing conditions. Another inclusion criterion was that the participants must have had experience in working with groups of participants. Although the focus of this work was sexual health, working in these topics was not a requirement given that it severely hindered the available population that could be invited to participate. The other requirement was that the participants needed to be able to speak either English or Portuguese. With these in mind, potential participants were recruited based on their prior publications and researcher's personal contacts, once a list was developed, they were all contacted via email. Eleven interviews were conducted with around thirteen hours of audio recordings. These interviews took around one hour each and audio recordings were taken.

The goal for the focus groups was to test the methodologies gathered from the interviews with real possible users of the service and see how they worked when dealing with stigmatizing topics, therefore the sampling was widely different. This stage required participants to be older than fifty-five years old and being able to speak either Portuguese or English. Participants were recruited from Fraunhofer AICOS cohort named COLABORAR – a group of people who volunteer to take part in research studies conducted by Fraunhofer AICOS.

For the observation, participants were professionals from Fraunhofer AICOS and external, which means they were used to working with research and some of them knew each other before this session, which might have some influence about their comfortableness. This participants were chosen because it was important to test the methodologies with people that will be utilizing them in their professional lives, this way it was possible to evaluate the methodologies from an expert point-of-view.

4.1.3. Data Collection

For data collection, three different methods were used: interviews, focus groups and observation. A sequence was used to gather the data and apply it in the next stage, therefore it is important to follow the stages in their specified order. During the sessions pictures were taken to illustrate the mood and to showcase some of the materials that were used during the workshop, excluding the interviews.

4.1.3.1. Interviews

The first stage was the in-depth interviews, where design researchers and designers were interviewed to gather information about how they conducted their work, the main barriers they faced and how they dealt with them. This would serve as starting point for practical side of this dissertation. After this, it was established a knowledge of the area and problems it faced as well as some of the methods that could possibly be used to solve problems in various stages, whether they are in the beginning stage of planning and recruiting or in the actual work sessions. All these interviews were conducted online on Microsoft Teams and recorded with the participant's consent, the interviews were transcribed in verbatim after so that they could be analyzed.

The interviews started by having a small bit of casual conversation with the participants, this was done to break the initial ice of speaking with strangers, the conversations ranged from personal interests to the scope of the present work. When it felt like it was the time to introduce

the theme an opening question was used to allow the participant to speak freely about the topics, the question used was “Can you tell me about an experience that you had that you feel had a big impact on you and your researcher?”. A list of topics to be touched upon with the aid of follow-up questions to the information the interviewee was sharing was defined and it goes as follows:

- Main barriers and how they are overcome
- Main methods used in research
- What types of materials they use in their work, which work best
- How they plan their sessions, recruitment, icebreaking
- Reasons participants had to refuse to participate
- Things that make the session start to fail and how to counteract
- Importance of using new methods to help with research
- Advice for people working with these topics

4.1.3.2. Focus Groups

With the data collected from these interviews, a protocol was created to conduct three focus groups with possible users of the service to discuss sexual health services. The first focus group was directed towards ideation of what a mobile sexual health service could be and what it could do, the next two focus groups were focused on awareness, how the users discovered new sexual health related services, the only distinction between these two was that one had the stigmatizing topic obverted at first and built up while the other one was direct in the mentioning of sexual health. The main methods used for these focus groups were visual materials, ideation, creativity and humor. The sessions were recorded in both audio and video formats so they could later be reviewed and analyzed. Although the focus groups were mainly used to evaluate the methodologies discovered, the subjects addressed there were regarding service design and service dissemination.

Site: Fraunhofer AICOS

Researchers: 1 male and 1 female

Participants: Minimum age of participants was 55 and they were all Portuguese

Food: Cookies and water

Placement: one table with participants facing each other and the researchers in the edge of the table

4.1.3.2.1. Ideation

Participants: 4

Duration: 45 minutes

The main goal of this workshop was to use storytelling and visual materials to gather information regarding the possibilities of technology, particularly mobile apps, dealing with sexual health, what could be done, what were some functionalities that the apps could have that would be good for the participants to use.

The participants were prompted with a story about a distant future where technology was everywhere, even inside people’s homes and the said technology could help fix every single health problem that people had. They were given the scenario of an app that could help with sexual health and asked to give some functionalities that could be useful for them.

In the first stage of the focus group two stories were read regarding three older adults, composed of two couples and a widower, the main problematic of the story was the same, problems associated with sexual health and old age, but there were some particularities to each case given the fundamental differences of life of a married couple and a widow.

It was also given some allusive pictures of a couple and an individual man, so that participants had something to hold and associate with the story.

For the final stage of the session, the participants were given a series of visual materials depicting different ways to convey information, such as doctors, radios, tablets, phones, computers, friends and family and asked to order them from least favorite to favorite way of gathering health education.

4.1.3.2.2. Awareness Obverted Stigma

Participants: 3

Duration: 45 minutes

Following the results from the first focus group, it was decided that the story would be removed since it didn't carry a significative effect on the participants. The participants were given the same pictures from the first workshop with an addiction of a tablet, because some of the participants said that it was something they often used. The goal here is to test the methods of using visual materials, humor and creative outlets, to do this the structure of the focus group will be directed towards finding out how older adults discover new health related technologies, the stigmatizing topic won't be brought until the middle of the session so the participants don't feel the stigma of discussing sexual health right from the start.

The conversation began by having some casual conversation with the participants about topics that were unrelated to the research so there was a chance to break the initial ice. After this, the participants were exposed to the problematic at hand that was related to health devices and health technology, from this point on the discussion was free until the participants were given the visual materials they were supposed to organize and discuss and informed that the technology they were learning about was regarding sexual health.

4.1.3.2.3. Awareness Stigma

Participants: 3

Duration: 60 minutes

The third and final focus group used the same visual materials and methodologies from the previous session. Sharing the same initial casual conversation and the initial problematic exposition, but this time instead of addressing health in general, the discussion was heavily focused on sexual health and intimacy.

The participants were then encouraged to discuss the matter between themselves until it seemed like they were comfortable withing the group, when this moment surfaced, they were given the visual materials that they should organize and discuss their opinions with the rest of the group.

4.1.3.3. Observation

Finally, with the data gathered from both the previous stages, two fellow researchers conducted a workshop where the participants had to participate in several activities, from character creation to completing missions related to a sexual health service. This session used a lot of different methodologies such as storytelling, roleplaying, visual materials, humor, and character creation. The observation was conducted on site at Fraunhofer.

Researchers: 2 female researchers

Participants: 9 working professionals in the field of Design and Design Research

Food: fruit and cookies

Placement: 3 tables with 2 participants each, 1 table with 3 participants

Methods used in the workshop: Roleplaying, creativity, humour and visual materials

What was being observed:

- How did participants respond to the methods used?
- The feel of the room, was it awkward or was it lively?
- Were participants engaged in the participation?
- Did participants actually roleplayed or was it awkward?
- Non-planned observation to see what other things surfaced during the sessions that were not expect or pre-planned.

The observed workshop was divided into several sections. It began with an exposition of the experience and what was to be expected of the participants, there was also a very small theoretical introduction so that the context of the study.

The second stage was for the participants to use some created materials with writing prompts to create their own characters that would be used throughout the workshop, the materials had a spectrum that had some sexual health related characteristics to help with the creation. After this the participants were to introduce themselves as their character and incorporate the part fully.

This was followed by a coffee break to allow the participants to interact with each other and to do something else if they decided to.

After the break the participants were given a mission for their character to accomplish, they were related to the service being studied. When the missions were completed, participants must explain their solutions to the rest of the participants.

Finally, the workshop ends with participants strolling through a room with pictures allusive to Anathema, these pictures depict anatomical and metaphorical drawings of genitalia and other sexually charged images, when the strolling ends, participants should discuss what they saw, what they think of the images and how the pictures made them feel.

4.1.3.4. Feedback questionnaires

Except for the interviews, a short anonymous questionnaire was given to the participants after each session so they could share their opinions, rate the session and share their feelings. These

questionnaires had different structures so they could be adapted to the sessions that was being held, whether it was an observation or one of the three focus groups.

Participants were handed a questionnaire that had some affirmations about the session that was held, for them to evaluate from a scale that went from 1 (totally disagree) to 5 (totally agree). The questions for each session were different because the methods being reviewed were also different. The list of questions asked will be described next.

4.1.3.4.1. Ideation

- I felt comfortable during this experience
- The experience was challenging
- I had trouble responding to what was asked
- The story was captivating
- I felt good being creative
- I would repeat this experience

4.1.3.4.2. Awareness Obverted Stigma

This questionnaire was different from the rest because it focused on the methods of communication for health related services, the questionnaire gave the users a spectrum with words in each end for them to select where in the spectrum they prefer the affirmation to be.

- I prefer that communication is (Direct/Indirect)
- I like when communication is (Serious/Funny)
- The message should be (Technical/Simple)
- I'd rather that communication is (Realistic/Animated)
- I prefer (Reading/Listening)

The second part of the questionnaire asks about the importance participants give to certain affirmations, ranging from 1 (low importance) to 5 (high importance)

- Message
- Communication method

The third and final section asks the participants to evaluate the trust they have in certain means of communication, from 1 (low trust) to 5 (high trust)

- I trust Television
- I trust my Doctor
- I trust my Computer
- I trust my Smartphone

4.1.3.4.3. Awareness Stigma

- I felt comfortable during the experience
- The experience was challenging
- I had trouble responding to what was asked
- I felt good contributing for research
- I would repeat this experience

4.1.3.4.4. Observation

- I felt like knowing the other participants improved my ability to share my experience
- I feel like the use of humour helped me feel comfortable
- I feel like using made up characters and roleplay helped me feel more comfortable
- I felt overwhelmed by the amount of materials
- I feel like the workshop was too long
- I felt comfortable sharing my experience during the workshop
- I would participate again in similar workshops

4.1.4. Data Analysis

Thematic Analysis was applied to the transcripts made from the interviews. A bottom-up approach was held for developing this thematic analysis. It started by assigning codes to relevant pieces of information identified in the transcript. The identified codes were analyzed through their affinity with other codes which they could have some relationship, this set of related codes were then assigned to a category. Finally, those categories were grouped into major themes, that identified the macro-level topics that were discussed during the interviews. The following illustration represents this in a schematic way.

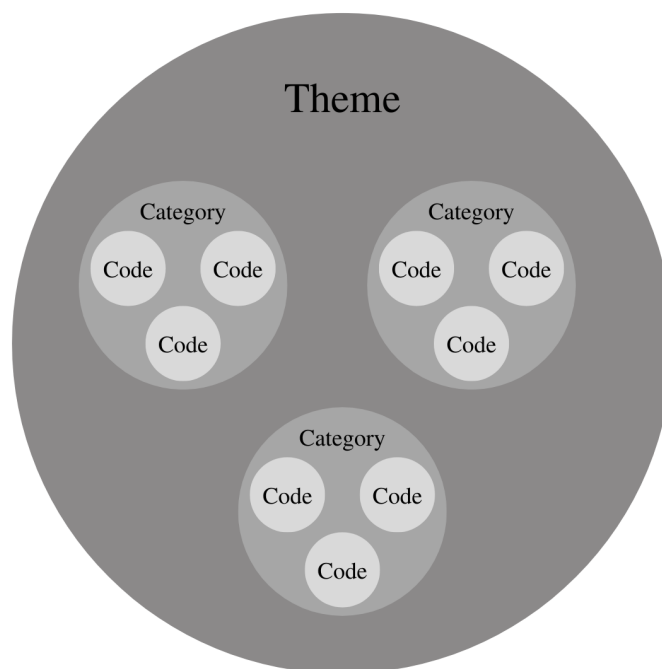


Figure 4 - Illustration about how the data is distributed during Thematic Analysis

5. Results

From the thematic analysis of the interviews resulted three themes that encompass all the data that was collected during the interview stage. They will be explained in further detail with examples next:

- **Self-Reflection:** Researching sensitive topics places an enormous responsibility upon the researcher’s shoulders, they need to reflect on what they are doing, what they are feeling and how to address it, research can have a deep impact on the lives of people, and it is very important that the researcher’s take this into consideration when deciding how they are going to approach something.
- **Participant Wellbeing:** Participants must deal with a lot of feelings and outside pressures when they suffer from stigmatizing conditions, this category encompasses those feelings and concerns as they were shared by the designers that work with them.
- **Tailoring Research:** Doing research around stigmatizing topics has a lot of particularities about the useable methodology, what needs to be considered during the whole occurrence of research, from recruitment to conducting the research sessions.

The following graphic illustrates the results from the thematic analysis in a schematic way, with the categories and themes fully present, but only some of the codes are used in the example, since there are many codes and would be non-essential information, for the full list of codes please refer to the appendix B.

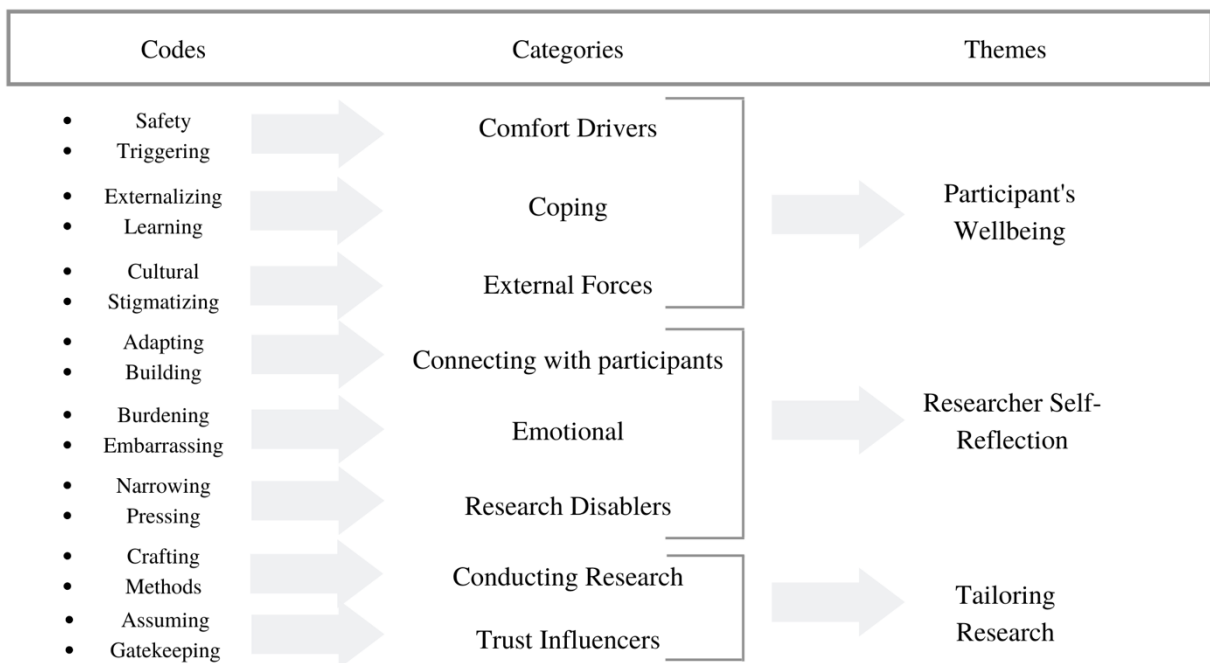


Figure 5 - Illustration of the results of the Thematic Analysis

The codes present in the illustration encompass sections of the interviews that seemed relevant for the work being developed, they gave some insight about various things that occur during research around stigmatizing topics. They were divided among eight different categories, namely:

- Comfort Drivers, these gather the codes that refer to things in research that have an impact in the participants comfort, both positively and negatively.
- Coping, the methods participants often use to cope with difficult situations during research.
- External forces, these are forces that are outside of the control of the researcher and the participant, such as cultural pressures and stigma.
- Connecting with participants refers to the strategies that researchers have that help in the process of creating connections with the participants.
- Emotional, these encompass all the emotional weight that the researcher has to carry when working with people that face stigmatizing conditions.
- Research Disablers, some factors that are partly outside of the researcher's control, such as deadlines and project goals which might interfere with the way the researcher is behaving.
- Conducting research refers to practical methodologies that researchers use in the various stages of research.
- Trust influencers, finally these are the factors that are present in the actual research sessions that influence participant's trust, this impact can be either positive or negative.

There was one key result that influences every research project around stigmatizing topics, personalization, along the development of this project it was clear that every step of the way required a very high degree of personalization and participant understanding. This knowledge is key because working with sensitive topics as some particularities that other types of research might not have, has found in the interviews, bringing up uncomfortable topics can cause harm to the participants or to the researchers, a good baseline knowledge can help prevent this, not only that but it can also greatly increase the probability of success of the research project. Although there is no one size fits all approach to conducting research on stigmatizing topics, there are some methodologies that professionals in the area commonly use, but nevertheless, the research should be tailored to the people it will be conducted with.

One method that was most commonly observed during the development of this work was the use of humor, humor was transversal to every single interaction that was held with participants whether it was in interviews, in focus groups, or in the observation. It was used not only purposely by the researchers to help lighten the mood and decrease the awkwardness and feelings of stigma, but it was also widely used by the participants to help share more personal and sensitive experiences without seeming to serious or embarrassed, it seemed like it was something that will naturally surface every time people are asked to share sensitive thoughts and experiences. As found in the interviews:

“work we might do around these stigmatized topics, doesn't necessarily have to be super serious and that in some way you can use humor and fun as a way to get around the awkwardness and the shame that might come with some of the topics we are interested in designing for.” – Quote from D05

This concept was also applied intentionally during the observed workshop, by utilizing a vial which was supposed to be a “love potion”, which got a lot of laughs right from the start of the session and also prompted some conversation between participants about the contents and what the “love” would be used for.



Figure 6 - Love Potion used during the observation

One other used method was roleplaying, which is a very effective way to allow participants to get out of themselves and adopt a persona that can serve as a vehicle for their opinions and experiences. When research touches upon sensitive topics people sometimes don't feel comfortable opening up and sharing their true thoughts, this can be counteracted by roleplay, since participants are sharing the character's opinions and not their own, so they externalize the feelings of stigma and shame from themselves, externalization is a key concept that really goes a long way in making participants feel safe and comfortable sharing controversial opinions, embarrassing experiences or things they are afraid to share. This happened during one of the interviewee's sessions:

“we asked them to roleplay something with the dolls that they had made and they acted it out some kind of interaction with these dolls” – Quote from D09

This method was also employed during the observation, which greatly corroborated the findings from the interviews, participants were very open to speak and share thoughts and opinions, not only that but when prompted to create a character some participants really put some thought on their characters and started doing voices and adding mannerisms that they thought their characters would have. This also touches upon one major concept that was found during the interviews, which was the sense of ownership, if the people participating feel like they own what they are doing or what they are contributing for it really decreases the feelings of stigma, during the observation when participants personalized their own characters it was clear that they owned their characters and decided what to do with them, this was a good coping mechanism for dealing with stigma associated with talking about sexual health and intimacy. They also were assigned missions that they should complete with their groups, this was a good bonding experience even though the mood shifted and participants started be more serious and focused on the task at hand, after this when they showed their solutions for the missions to the other groups, it generated a lot of lively discussion which was very helpful data-wise.



Figure 7 - Participants Sharing the results of the assignments during the session

One other thing that was very clear from this observation and validated by the interviews and focus groups was that the use of visual materials was very helpful for both the understanding of the assigned tasks but also as a way to help participants convey their messages and engage more vividly with other participants by comparing their character sheets. It was also something for the participants to hold and admire, which was something that they valued as seen by their responses in the feedback questionnaires.



Figure 8 - Visual Materials used during the Observation

Giving the participants visual materials is a very powerful way of communicating with them, used alongside providing some materials that allow them to unleash their creativity can really give them the tools to communicate fully what they sometimes can't really communicate verbally, during the focus groups, one participant used the pen and paper provided to start drawing something while explaining what they thought and to support their point of view during the discussion stage. This of course was a very low-detailed drawing but it still served as a medium of non-verbal communication that allows for feedback with greater detail.



Figure 9 - Drawing made by one of the focus groups participants

During the interview process one concept that surfaced very often was the concept of gatekeeping, which refers to people associated with the participants that have some power over them, these gatekeepers have a very big impact on research, but this impact sometimes can be negative, in the sense that it severely hinders the process of working with participants, this can be done in many ways, for example these people can shame the participants into not participating in the research or advise them against it, this happened to one of the researchers interviewed when working with students in a school:

“It was quite interesting when i was recruiting because i also went through the teachers and there among some of the teachers, they were really, let’s say they were not equally interested in the project” - Quote from D07

But this is not always the case, sometimes these gatekeepers use their deep understanding of the participant to help guide them or even act as a link between researcher and participant, helping the researcher know what to do and what not to do and the best approaches to have with that participant, for example:

“Who is in the workshop is as much important as who is facilitating it, when I work with support organizations and i do do workshops with people who use the services, I make sure a member of staff is around, something as simple as that, and it has happened that you know people started crying and the sessions had to stop for them to go and get support” - Quote from D09

One other thing that makes these gatekeepers very important for research is that they can really help build a relationship with the participant, because if the gatekeeper who is someone they trust is recommending the researcher or working with the researcher it can really help the participant see the researcher in a more positive light, a professional working with people in the health sector really noticed this:

“if you don't have the health practitioner who is like your gatekeeper in a way, to introduce you to these groups, it's very tricky and it just slows down the process so much in terms of what you can get there (data).” – Quote from D03

This relationship building is also key to address the research gaps previously mentioned, research around stigma requires participants to provide a lot of personal and often traumatic information about themselves, it is very difficult to do so with a stranger in which we don't trust, this often makes participants avoid sharing their opinion or just refuse to participate in the sessions. It is imperative that researchers whenever possible try to build trust with the participants and understand them, like previously mentioned the participant understanding can be a big driver of trust, in the sense that the researcher does not bring up methods or topics that will make the participant uncomfortable nor do they use methodologies that might cause harm to the participant.

Of course that building this understanding and trust takes time, and very often researchers do not have time, which might cause them to narrow their view of the participants and the project to their project timeline, this is something that can severely hinder the data collected, in these topics participants need to feel in total control of the situation, trying to force them to do things quickly or not opening the possibility of rescheduling or stopping the session will have a very negative impact on the relationships with the participants and worst, it will negatively affect the idea that person has of research, which might cause them to avoid participating in future project.

Having this self-reflection as a researcher is very important, not only for the participant's safety but also for the researcher's safety as well. In this line of work, it is inevitable that very sensitive topics and feelings will come up during the sessions, sometimes even very traumatizing events in the persons lives, and it is very common that the participants look for the researchers for comfort and see them as confidants. This is not necessarily a bad thing, but it is very important that boundaries are set so that no one feels uncomfortable, another thing that is very important to have, as suggested by the interviews, is that the researchers should build support networks for themselves and have some resources at hand to direct the participants to when they start feeling increasingly upset, one of the interviewees went as far as to suggest that researchers in this field should have some counseling training, not to act as counselors, but to know how to address the more acute situations when they arise. One example of this, was this snippet from an interview:

“where they would just speak, they would vent out, they would just share their struggles, they would break down during conversation and as a researcher, it would affect me, because those struggles are not very pleasant to hear” – Quote from D10

This training paired with the understanding of the people we are working with as researchers can have a very positive impact in preventing very harmful situations to arise, even though that not every situation is preventable as people can sometimes act or feel in other ways that are not expected, a very negative example of an upset participants was shared by a researcher, it goes as follows:

“but he out of the blue he sort of got me into a bit of a headlock and was a bit aggressive and you know, he's not able to verbally explain why that was and so that was really difficult for me” – Quote from D06

These types of situations were also very present in other interviews, not necessarily so severe but with some variations, whether they refer to participants breaking down, admitting something that was illegal or doing something that got the other participants to feel very uncomfortable. This requires that the researchers are very good at thinking on their feet and adapting the research mid-session to address the situations that might arise, this is something that is probably transversal to all types of research but it is specially notorious when dealing with sensitive topics, this was a concern that was found throughout during the interview stage, here follows one example:

“I think also considering the risk your research might have and how you are going to mitigate those risks, so really carefully thinking through the strategies of what happens if a person divulges something that is illegal or what happens if a person tells you something you know it's clear they have been abused” - D05

A situation that required some adapting also surfaced during the focus groups when a participant made a remark about homosexuality that other participant found offensive and prompted them to start having a more heated discussion about the topic, fortunately it ended shortly after that just by changing the topic and refocusing the participants attention on the discussion being held.

It is also key for the participant's wellbeing, since researcher's never really understand what the participants are dealing with outside of the research and how much their stigmatizing conditions might be affecting their lives, understanding the weight that research carries is very important to guarantee that the participants have positive experiences and do not resurface trauma or other mental health related conditions, this was a big concern for one researcher:

“These are some of the things that I've learned from them which are not very easy, just having good intentions it's not going to work, you need to have a good field partner who can tell you that 'you know this might end up with you being in jail or this might end up with you affecting someone's life in such a bad way that it might even cost their life'” – Quote from D10

The before-mentioned understanding has other impacts other than emotional damage or preventing emotional damage, they also have a big influence on what methods the researcher should be using, one example of this, was during the first focus group, it was decided to apply utopian ideation, which means that participants were asked to picture something that does not exist in the realm of what an application could do for sexual health. Although the interviews had positive insights about the use of this method, in this specific context it did not work, the reason being that participants did not have enough technological literacy to be able to think creatively about things that did not exist, instead, they referred to features and functionalities that they already had seen when using their smartphones. Therefore it is very important to know beforehand if the participants have sufficient knowledge about the topic to be able to think about it creatively and imagine new scenarios.

Unfortunately, there are a lot of other external forces present in research that are outside of the control of the researchers, as seen before with gatekeepers that sabotage the research, sometimes these gatekeepers are led by cultural values and norms to act the way they do. Culture is very heavy on research, certain topics are highly stigmatizing in some cultures, they are taboo even to the extent of both researchers and participants losing personal relationships with friends and family just by researching or participating in the taboo topics. This is the reason some researchers are trying to use their research and platform to enact institutional change and have an impact on how some themes are perceived by certain cultures, one example of this:

“i think it was important for me to work with the stigmatized topic, not on a individualized level, but to address in a more systemic way because i think that we don't only design individual technologies and make the stigmatized topics the individuals responsibility but really raise it in a more systemic or institutional level.” - Quote from D07

Culture can also impact the methods used in certain situations, even humour which is something that is generally accepted by most people while working on these topics is not applicable to every single situation, and culture has a say in this as a researcher found when it moved from the United Kingdom to Northern Europe to work on a project:

“ Now i realize having moved to Sweden, it is also quite cultural like the UK has a particular sense of humor,” - Quote from D05

Other than culture, stigma itself is also a very powerful external force that deeply impact research, often times making people avoid participant in research that might bring forth these feelings, even if when people agree to participate in something that they know will be stigmatizing, they sometimes cannot rid themselves of the feeling, even when they are already sharing something personal, this happened to a participant of a researcher that was interviewed:

“from your previous life do you feel is really missing?” one of them was like "i miss sex" and then apologized right away, said, well, you asked, and no one in the literature comes barely across, that is not a thing that is really emphasized” - D03

For example, in this case the participant immediately after answering a question felt the need to apologize for what they said just because the topic was sensitive and related with sexual health and intimacy.

Fear or uncomfortableness in sharing things related to sexual health and intimacy is very common, in some cultures this feeling is even more exacerbated by the instituted norms, something that researchers in this area need to take into account is the fact that sometimes participants when talking about something sexual or intimate, whether it is hygiene related or about any sexual disease, participants often look for researchers of the same gender as them to share, this appeared during the interviews and once again during the focus groups where when the topic shifted to clear sexual discussions, the female participants ignored the male researcher and started to speak directly to the female researcher, the same was found for the opposite gender, where the male participant looked for the male researcher and ignored the female. This was also visible during the observation stage, but not with researchers, it came to a point where participants were to navigate through a place with several depictions of genitalia so they could later talk about it, during the early stages of this section the participants divided themselves into gender-specific groups and discussed among themselves the pictures and made some remarks about their appearance, even making some jokes regarding some of them, the groups dissolved later though.

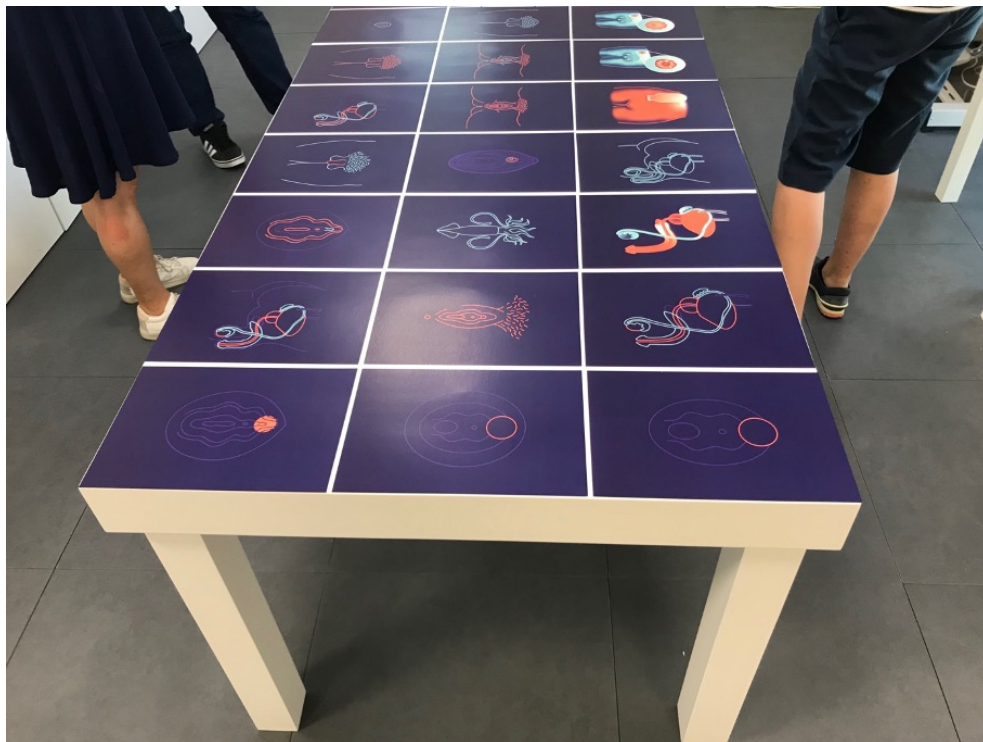


Figure 10 - Provocative imagery shown to the participants in the observation

From the data gathered in this section, from the interviews and methodologies tested on the focus groups and observation, the following table was developed to summarize the methods used, how they are used in research and some considerations that researchers must have when using them, because some of them have some specific particularities.

Method	What is it for	Considerations
Storytelling	Good outlet for externalization, it allows participants to think about sensitive topics as characters instead of themselves. It helps people share their honest opinions without perceiving the associated judgment	The story needs to be captivating, otherwise, it will be left soon after it is told, although even when dropped it still acts as a good starter to help participants break the initial ice
Humor	Humor is present all around in sensitive and stigmatizing topics as it greatly lowers uncomfortable feelings and initial awkwardness between participants and researchers. Humor can be intentionally brought by the researcher but even when it was not intentional it came up during every stage of this work.	There is although a fine line that needs to be taken into account when using humor in research, like everything else in working with sensitive topics, different people require different types of methods, when using humor it is important to make sure that the participants are open to that sort of interaction, humor can be beneficial but it can also be very detrimental in the sense that participants can feel disrespected.
Researchers from both genders	When discussing gender-specific questions, participants tend to look for people of the same gender, especially when discussing subjects of intimate mater such as sexuality, STD or hygiene.	This is not only reserved for the researcher but also to other participants. During sessions where heavily gender-specific topics came up, participants gathered into same-gender groups to discuss them. It is important to mention that this was observed during research on sexual health topics, it might not be seen in other topics.

<p>Visual Materials</p>	<p>Having something to help illustrate what participants are supposed to be doing or seeing is very useful to avoid miscommunications. It is also a good way to help participants communicate between themselves and with the research team as it helps in conveying messages.</p>	<p>Visual materials do not need to be very high quality or very well designed, sometimes even visual materials can be built during the session and given to the participants.</p>
<p>Creativity</p>	<p>It is good practice to always have a pen and paper available in case the participants want to non-verbally communicate something. It might be through drawing or writing but it also facilitates comprehension and gives participants more freedom on expressing themselves in the way they see fit</p>	<p>In this work participants had pen and paper but it seems like any creative outlet is good, whether it is sewing, collaging or etc.</p>
<p>Utopian Ideation</p>	<p>Utopian Ideation is a good way to get participants to think on solutions, features, and characteristics they would like to be designed in the services that are being created for them. Or at least the direction in which future users would like to see the service go.</p>	<p>It is very important to understand the participants where this is going to be applied, if the participants are not somewhat familiar with the subject of the study, for example using utopian ideation to develop technology with people with low technological literacy will not work because they will not have the tools and knowledge to think creatively.</p>
<p>Roleplaying</p>	<p>This proved as an exceptional method of engagement, participants playing a part, or even better, a character they built themselves is a very good icebreaker, people are more open to sharing their opinions, thoughts, and fears when they are speaking through the voice of someone else. It is not only a great icebreaker but also a great way for participants to interact with each other.</p>	<p>Roleplaying takes a bit more work to pull off than the other options mentioned in this paper, mainly because it requires creating narratives, characters, and organization so the participants stay on track and the session does not get carried away.</p>

<p>Externalization</p>	<p>This is something that can be prompted by some of the before-mentioned methods. It is a very powerful feeling and a very good way for participants to let go of the awkwardness or even the pain they experience if they suffer from stigmatization by their peers and culture, which can act as a very big inhibitor for research and for their lives as well.</p>	<p>Externalization is difficult to achieve, it is not simple to make people feel outside of themselves, especially when discussing topics that are very close to them, but if accomplished it has a great positive impact on the research being developed</p>
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Table 1 - Table of the resulting guidelines for applying the methodologies tested

6. Discussion

This thesis allowed the researchers to be aware of certain pitfalls that they need to consider when conducting their work, namely the pressings of deadlines and narrow views of the research and thus forgetting that the participants have needs that need to be addressed in order for the research to be successful and respectful. Not only this but also the external factors such as cultural pressings and stigma which also create steep barriers that researchers need to be able to overcome. The results of this thesis are related to the methods that researchers can use in order to overcome these barriers and the things they need to consider to apply these methodologies to each specific situation.

Referring again to the reflexivity and institutional change mentioned in the literature review of this project (Vink & Koskela-Huotari, 2022), it is clear from the data gathered that this are some of the concerns researchers have when they are developing their work among stigmatizing conditions. Most researchers make use of this self-reflection to evaluate themselves but also the weight their research might have, both positive and negative, the negative impact can bring participants down, resurface negative feelings or even make some participants see research in a bad light, creating then stigma towards research. But, it also has the potential to enact positive outcomes, on a personal level the participants might have an outlet for their feelings and contribute to something greater, this something can be institutional change, like mentioned before, both participants and researchers are sometimes motivated to do their work because they want to create change in the world that surrounds them.

These changes can even have a positive impact for future research, by changing the way it is perceive by people, this type of cultural shift is key in the field of stigma, as mentioned previously, stigma still is a big presence in most people's lives and the demographic studied in this work is no different.

Now, addressing some of the methodologies studied during this work, it is important to start by reinforcing the idea that personalization is imperative for the success of research in this field, dealing with very sensitive topics required a personal touch to allow participants to feel comfortable and safe. These feelings from the participants are some of the most important drivers of research success, and well-designed research can go a long way in bringing them forth. Feelings of safety, ownership and trust are some of the emotional keys that deeply impact the research, these should be looked for in every session, because they also counteract the negative feelings of pressure, fear and power imbalance that are also very often seen during work in this field.

Another emotional driver that is very important and surfaced not only during the data gathering sections but, before that, during the review as well, was humor, it is clear that humor is a very present force during stigmatizing research although it must be used carefully so it is not perceived as disrespectful, when used right paired with other methods of course, since humor on its own does not constitute a method, is a very good way to remove the bad feelings people have while addressing difficult subjects. In previous work in the field of sexual health, humor was used to mitigate the problem with addressing sensitive topics which are often considered taboo, by making the subjects feel more comfortable it was easier for the users to engage with technology. Humor in general is seen as a positive feeling and as such, it enforces positive attitudes towards the topic being studied. (Almeida et al., 2016; Wood et al., 2017).

Something that did not come up during the review was the use of researchers from both genders, it was something that was suggested during one of the interviews and it was very clearly observed during the different stages of data gathering, it seems like this is something that researchers really need to take into account when they are addressing topics that might have some gender-specific overtones, such as the ones seen during the focus groups, regarding sexual health and intimacy. Conducting the focus groups and the observation really helped validating this particularity because it was very notoriously present.

On the practical methods that were employed, starting by the utopian ideation, like discussed previously, there is some merit to the method since it can bring valuable results especially for gathering information by boosting the participants creativity, it was not successfully employed during the focus groups, so it is important to make sure that the people working with the researcher have enough knowledge to address the tasks being given, still the participants were engaged by the prospect of trying to be inventive. It seems like people really resonate with this possibility of letting out their creativity, therefore the researchers should provide them with the tools to do so. As seen by the previous sections, people also respond well to having something visual to relate to and use, even if they are not the ones creating the visual materials being used, it is still appreciated that some tangible resources are present so the participants can touch and interact with.

Storytelling also proved to be a very good method for people to start talking and interacting with each other, it seemed like researchers can really take advantage of this method to get participants to engage with each other and forget the weight of research. Paired with tasks such as creating characters and solving problems and missions as those characters, the possibility of participants forgetting this weight is even greater.

One major gap identified was that researchers in this field don't take the time to know their users and perpetuate some of the methodologies that are a bit outdated and are not transferable to working around stigma and intimacy, namely, the use of archetypes and personas which deviate the focus from the human to some imagined person created through the perceptions of the researcher. The understanding required to work around these topics, as mentioned previously, is key for success, therefore researchers could use some of the ways presented in this work to address that lack of knowledge, from using gatekeepers that know the participants to help with building trust and consequently knowledge or doing this approach through the longer way by for example being active in the participant's community. Researchers in this field have to do some extra steps if they want to guarantee that their work is successful and can have positive impacts both inside and outside research.

This work approached various methods of tailoring research and tested them, from that came some guidelines regarding how to apply and when to apply these methods, some of them had a good impact regarding the main subject of this work, which fundamentally is to decrease the feelings of stigma in research. Other than just discussing the practical methods this research also gave some insights about some of the considerations researchers have to take into account when working with these topics, whether they are emotional or cultural, they have a very high impact on the results of research.

In the end the work here presented addressed some of the research gaps that are present in the field of design research and made some suggestions on some of the methods that can possibly fill some of those gaps or at least diminish their negative impacts on research from an holistic perspective, encompassing not just the work but also the people involved, whether they are researchers or participants.

7. Conclusion

The present dissertation focused on studying the research methods utilized when working around stigmatizing topics in Design and HCI, in order to improve the way it is done currently. Anathema, which is an online-base sexual health promotion programme, served as the baseline for this dissertation where users were studied using the methodologies gathered from professionals with the goal of testing those said methodologies with real users on stigmatizing topics, using as a pretext gathering service design insights from those users amidst discussions of sexual health and intimacy which can be stigmatizing.

In order to build a base of knowledge a literature review was conducted addressing several topics considered to be relevant for this research, such as, Design Emotion, Stigma, Inclusive Design, HCI and Sexual Health and finally Service Design in Healthcare.

With that base of information it was decided that the work would be approached through the lens of qualitative research, for several methodologies were selected to gather the required data to address the research questions previously defined. There was, like exposed before, a work plan that detailed the order in which the methodologies would be applied since many were used. Starting with Interviews that acted as a mean to get expert opinions on the subject, which were later analyzed to build a protocol for three distinct focus groups with possible users of the service and once again using the data gathered there to create a new protocol to be applied by fellow researchers, in which an observation was made to evaluate how that protocol worked in the field.

From the methodologies gathered, it was possible to conclude that some of them proved to be very effective when discussing difficult topics, namely:

- Humor, which appeared in every single stage of this dissertation both on purpose and organically, because it seems like it is still one of the best methods to counteract the negative influence of stigma and judgement
- Roleplaying and consequently externalization, given participants a way to speak outside of themselves by using characters and materials was a very powerful way to start conversations without the heaviness of sensitive discussions, since participants felt they were speaking for their characters and not for themselves
- Researchers of both genders, this was a key finding for conducting research which was mentioned in the initial stages of research and test later during the focus groups, it was very clear that participants preferred to address sexual imbued topics with people of their own gender
- Visual materials, once again the use of materials was a good way to explain to the participants what their tasks were and also giving them something to hold while talking and interacting with other participants
- Creative outlet, it is also a good practice to have paper and any writing instruments near the participants so they can draw and write when they feel like it, it can be a good way for them to share without having to struggle with speaking for a whole group directly
- One thing that became clear from the data gathered and from the tests was that researching stigmatizing or sensitive topics requires a very high degree of personalization which is only possible by doing some intensive research on the participants beforehand. This research does not guarantee that it will go well and generate good data, because another thing that is very important is the researcher's ability to adapt to the circumstances at hand, but it greatly improves the odds of success
- Although it did not work during this work, the use of Utopian Ideation still shows promise, because even though the results of the methodology were not good enough for

the objectives of the focus group, participants gave very positive feedback regarding using their imagination and trying to think creatively on things that did not exist, it also was observed that they were engaged in the session and vividly discussing with each other.

Finally, the methodologies were evaluated and discussed, resulting in a guideline to employ the various methods tested as well as what to consider both before and during the application of the said methods. Although some contributions were made to the body of knowledge within the field of Design work around stigmatizing conditions, given the early stages of the service development there is still further research to be made where the methodologies gathered in this dissertation can be further explored.

8. Limitations and future work

The present work had some limitations during the course of its development, most present during the data collection stage of research, given the sensitivity of the topic it was challenging to gather participants for each of the sessions, especially during focus groups where the groups being studied were older adults. Therefore, the cohort of COLABORAR from Fraunhofer provided the participants for these sessions. It is important to share as a disclaimer that some of these participants were already familiar with participating in research projects around health and digital technology, not necessarily regarding stigma, but still there might be a recruitment bias or a slight bias to their opinions.

The same occurred with the observation stage, where the participants were researchers who were helping evaluate the methodologies proposed. These researchers were not strangers to discussing stigmatizing conditions during their professional lives, therefore they might have some “resistance” to the looming presence of stigma.

It is also important to add that the participants of the interviews were from all around the globe, which means that they worked in very different cultural settings. Therefore it is good to know that some of the methodologies suggested by them as well as possible characteristics they found in their participants and themselves might be culture specific.

Regarding the results themselves, this research provided with a copious amount of data concerning methodologies. Given the available time and resources for the research project, it was not possible to test all these methods, so a few had to be selected.

As a future research opportunity it would be interesting to explore the methods that were not used here and expand on the created knowledge of guides for methodology application presented here in this thesis. This would be especially interesting by testing the proposition of creating relationships with the participants which will take a large amount of time doing the work required before the actual research takes place, but since it was a subject that came up very often during the data collection stage, it poses a great opportunity for discovery. All these contributions to the state of the art of design research around stigma would support researchers to conduct their research in a very positive and effective way and even possibly create meaningful change in their communities.

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APPENDIX

APPENDIX A – Interview Protocol

Background

What works:

Humor generally helps participants feel more comfortable

Group work helps people empathize with each other, often people end up motivating the other group members to speak up, although this requires good moderation so that some members of the group do not overtake the conversation

Sometimes providing activities and games can provide a nice way to break the initial ice and get people to share without associating the usual stigma related to the questions

Great at helping people bring forth meaning to health related subjects in a social setting

What does not work

Being too clinical raises stigma and discomfort in participants, but there is a fine line between being too clinical and not clinical enough, the same goes for humor, people do not like too clinical but also they do not enjoy too humorous because it might be confused with mocking or not taking their concerns and feelings seriously

Participants that have some characteristics in common have an easier way talking about sensitive subjects because of empathy and similar shared experiences

General Ideas:

Some of the previously mentioned topics vary with participant age and culture

Proposed the use of activity-oriented questions for health research topics as an enrichment of data collection and a means of making it easier to talk about sensitive and complex topics

Research questions

EN: What are the barriers Design Researchers experience and what strategies have they devised to research stigmatizing topics in group user research activities?

PT: Quais são as barreiras sentidas por investigadores em design e que estratégias desenvolveram para trabalhar com tópicos estigmatizantes em sessões de grupo?

Keywords:

EN: Group user research sessions, stigma;

PT: Sessões de grupo, estigma.

Participants

Design researchers that work with stigmatizing topics. This stigma encompasses only conditions that bring forth strong reactions and feelings among peers and other individuals, such as fear, violence and exclusion. Some examples are individuals that have noticeable diseases, people with severe addiction or people with conditions that affect sensitive topics such as sexuality and intimate life.

Exclusão:

Sem experiência em trabalhar com grupos

Sem experiência em trabalhar com tópicos estigmatizantes

Não saber falar inglês nem português

Inclusão:

Experiência em trabalhar com tópicos estigmatizantes
Trabalhar em design research
Experiência em organizar sessões de grupo para design
Caracterização demográfica:

Script

Introduction

Muito obrigado por ter aceite estar aqui hoje, o meu nome é Diogo Coutinho sou aluno finalista do Mestrado de Engenharia de Serviços e Gestão na Faculdade de Engenharia da Universidade do Porto e estou a desenvolver a minha tese que tem como objetivo diminuir o sentimento de estigma em design research, estou a trabalhar com o apoio da Fraunhofer AICOS no projeto Anathema, um projeto de saúde digital que visa a utilização de dispositivos móveis para ajudar utilizadores a ter vidas sexuais ativas e saudáveis

Icebreaker

(Possíveis questões para icebreaking) Olá, como está? Antes de mais quero agradecer por ter aceite o meu convite para esta entrevista

Esteve em alguma conferência recentemente?

Visitou alguma exposição recentemente?

Leu algum livro recentemente

Narrative Interview

O meu objetivo é perceber com algum detalhe a sua experiência e, por isso, vou centrar a entrevista em casos reais que tenha experienciado.

Pode contar-me sobre uma experiência mais marcante que teve no seu trabalho com grupos em contexto de design?

Needed topics

Principais dificuldades e como lida com elas

Principais métodos que usa

Que tipo de materiais costuma usar no trabalho, quais os que obtêm melhores resultados

Como funciona o planeamento das sessões? Recrutamento, aceitação, como quebrar o gelo

Motivos para rejeição de participação

Coisas que fazem com que a sessão comece a correr mal, como contrariar

Importância de utilizar novos métodos para facilitar o design research

Que conselhos daria para pessoas que trabalham com estes tópicos (lessons learned)

O que se deve evitar?

Ending

Antes de dar como terminada a entrevista, há mais alguma informação que considere pertinente que ainda não foi abordada?

Muito obrigado por ter aceite fazer parte desta entrevista e pelo seu contributo.

APPENDIX B – Thematic Analysis Codes, Categories and Themes

Codes

Name	Description	Files	References
Failing	Failures that happened during the research	9	27
Negative	This code serves as a complement for other codes, this will be exemplified after this table	7	26
Participant Wellbeing	Theme		
Comfort drivers	Category		
Safety	Situations where the need to feel safe and it's importance came up	6	20
Triggering	Situations where the participants were triggered or might be triggered by something in the session, such as materials, other participants or the researcher	2	2
Coping	Category		
Externalizing	Exteriorizing stigma from the people	4	5
Learning	Participants or researchers learn something	4	6
Owning	Let people own their decisions and own what they create	7	31
External forces	Category	0	0
Cultural	Culture where the participants are inserted on and how It affects the participants and their ability to participate in the research	8	27
Stigmatizing	Stigma that place it's burden upon the participants and it's impact on the research	5	16
Positive	This code serves as a complement for other codes, this will be exemplified after this table	11	40
Researcher Self-Reflection	Theme		
Connecting with participants	Category		
Adapting	Being able to adapt to certain situations that were not expected and would have a negative impact	8	28
Building	Building a baseline of knowledge and relationships before starting the	7	25

Name	Description	Files	References
	research		
Relating	Creating relationships through empathizing with what the participants are feeling	9	28
Understanding	Understanding your audience	8	43
Emotional	Category		
Burdening	Researchers need to carry a burden when dealing with emotional situations	2	9
Embarassing	Feeling embarrassed to share	1	3
Reflecting	Instances of self-evaluation and reflection	6	27
Supporting	Support nets for the researchers that deal with difficult topics	2	4
Research Disablers	Category		
Narrowing	Seeing only the problem and not the people	2	5
Pressing	Pressure and rush to make things happen	2	5
Tailoring Research	Theme		
Conducting Research	Category		
Crafting	Creating things that were specific for an audience or session	9	33
Humor	Instances where humor was used or present	5	12
Icebreaking	What was used to break the initial ice in sessions	5	7
Method	Methods used for the research	9	30
Recruiting	Information about the recruitment of participants, from problems to advice on how to conduct it successfully	7	24
Testing	Testing the methodology, materials or prototypes	5	12
Trust Influencers	Category		
Assuming	Making assumptions	4	10
Community	Feeling of community and creating communities	5	9
Feeling	Instances where feelings where exteriorized or mentioned in a way that impacted the research	10	30
Gatekeeping	Instances where people related to the	10	52

Name	Description	Files	References
	participants intervened in the research, both positively and negatively		
Overting	Hiding information on purpose, for the benefit of the participants and research	4	6
Teaching	Researchers or organizations teach something	5	8

Table 2 - List of Codes, Categories and Themes

The following tables are examples of the queries made with the “Positive” and “Negative” codes to help better classify some of the other codes.

Gatekeeping - Positive		
but then finding someone who wants to talk about it is another issue, so really getting participants takes a while you need to build up a rapport, you need to ideally find a health practitioner who can point you towards people	if you don't have the health practitioner who is like your gatekeeper in a way, to introduce you to these groups, it's very tricky and it just slows down the process so much in terms of what you can get there (data).	we worked with this doctor and we had issues understanding the problem, so he invited us to up to where he lived for 2 or 3 days to interview those children, they were around 8 to 10 and i thought that worked really well, i thought that if we didn't have him as a helper, well he was a client in a way, he paid us, but that would have been impossible,
we only had those 3 days and we had a lot of people lined up, the doctor gave us one of his assistants to manage all of this, which was super important as well because she knew the people	she knows this issue she will just bring it up at some point during the conversation if she felt it got stuck so she helped us in that regard	so someone needs to give you some training so you are a bit aware and then you're still not perfect, you're still relying on someone that comes from their culture is really, it makes your experience as a researcher better so you're not insensitive.

Table 3 - Query results for "Positive Gatekeeping"

Gatekeeping - Negative

<p>eram os pais que tinham de assinar e neste caso os pais não queriam que elas participassem</p>	<p>we proposed this idea to the parents and they were like "no way, no way is this a good idea"</p>	<p>a medical discipline things sometimes, from my experience, not everyone, but sometimes they can be a bit "i already have an idea, this is the problem" and then they just want you as a designer to just give it a nice form</p>
<p>then i think it's a bit of a power struggle and to really get to them what your value really is in the project and that you're not just making something pretty but that you could really contribute to give them a broader perspective as well</p>	<p>i found it really difficult to connect with the support staff working there, like incredibly difficult, i don't know if you've been in one of these environments but, basically i found that most of the staff members working in this ward with 9 autistic defendants, they kind of locked themselves up in the office which was like a goldfish bowl that looked out to all the guys living in this space and it was a weird environment and they were not supportive of me being there</p>	<p>It was quite interesting when i was recruiting because i also went through the teachers and there among some of the teachers, they were really, lets say they were not equally interested in the project</p>

Table 4 - Querie results for "Negative Gatekeeping"

<p style="text-align: center;">Feeling - Positive</p>		
<p>i was really amazed in to what extent they took all of that in their stride, there was maybe a bit of nervous giggle, as we have in this conversation here, but that was about it</p>	<p>she was very passionate about it and it was nice, because we both felt we could contribute something to it, and she had awesome ideas because it was her experience not mine, so that was really nice</p>	<p>It was a quite, there was a lot of laughter, a lot of people laughing</p>
<p>is when you grow up you lost the sense of fun, it is mostly transactional, why don't you think of that hour as fun for yourself and the participants, they can explore all the childlike things, give them blocks, give them colors, give them paper, give them whiteboards, give them artifacts, push them to do something that they do not do in their usual lives, they might enjoy doing that</p>	<p>i know it sounds weird, but i do feel honored about the fact that i work on aspects that are really relevant, that are my personal beliefs, that are my values</p>	<p>that kind of appreciation and more joyful approach and highlighting that, i think that aslo could be, i think thats a really important different atitude</p>

Table 5 - Querie results for "Positive Feeling"

Feeling - Negative		
it was like a high security ward environment, it was quite depressing space really	in actual fact they said things that made me really scared to engage with the defendants	porque as pessoas ficam um bocado intimidadas
i like creative things but also a creative so not everyone likes those and but like sketching or stickers and stuff like that i think are super nice, but of course some people felt very uncomfortable with it and it's just not nice for them	what was challenging was when I had conversations with the parents when I say parents I mean birthmother and father. The fathers were so uncomfortable,	if they say no it's fine you move on, but if you propose it three more times it's just very insensitive, so that was awkward as a participant.

Table 6 - Querie results for "Negative Feeling"

APPENDIX C – Observation Notes and questionnaire results

Setting

Site: Fraunhofer

Researchers: 2 female researchers

Participants: 9

Food: fruit and cookies

Placement: 3 tables with 2 participants each, 1 table with 3 participants

Introduction

The workshops began with an exposition of the experience and what was to be expected of the participants (transparency)

There was also a small theoretical introduction so that participants could better understand the context of what was being studied

Humor was used to try and lighten the mood of talking about sensitive subjects

Some artifacts were used to create a sensation of “out of reality”, a “love potion” was distributed through the tables with participants to aid in the discussion, this potion consisted in small paper hearts of various colors and patterns

Character creation

The activities began with an individual exercise that prompted the participants to create their own individual personas by using one character card that had different spectrums of choice regarding gender and sexuality

During this section one of the groups was very excited and talkative, when they did not know the meaning of something (for example, intersexual) they asked each other.

The creation of characters brought up a sense of exteriorizing the problem and stigma, some of the participants even said things like “Então não sou eu!” (So this isn’t me) or “A personagem não sou eu” (The character isn’t me)

Other groups stayed in silence during the process of character creation and very focused on the task

Some participants feared that not knowing what the meaning of some words were would affect what they could do or say, that was a barrier

One of the participants used an online randomizer to create their character, it is unclear if this choice was made because the participant felt the need to exteriorize themselves even more from that character or if it was derived by their lack of knowledge of the topics

Some participants had trouble naming their character

When the groups finished creating their characters they kept talking and making jokes about each other's characters, the mood was very light and fun at this point

Character Presentation

After the characters were created and named, the participants were asked to introduce themselves to the whole room as their character.

No one wanted to start, although this feels very usual in these type of workshops, whether they are addressing sensitive topics or not.

At this point, the introductions felt like a Role-playing game were some participants actually played their characters by doing voices and introducing mannerisms that they imagined the character having.

Only 2 of the participants played characters that were not health.

One of the participants said something curious “I’m a man because the doctor said so”. The aura of gaming was so present that one of the participants named their character after a video game character.

Near the end of this section the participants were talking to each other to see if any of their characters was compatible with another so they could potentially form a couple.

Participant feedback for this section

They enjoyed having the physical artifacts to interact with, the character card for example, was a success.

They appreciated the aid of trigger questions to help create their characters.

One of the participants said that it was fun to “entrar nos sapatos dos personagens” (Walk in the character’s shoes).

The provocative questions and environment were welcomed.

Coffee break

Most participants stayed in the room and gathered in groups to speak about the session and to make jokes and bond.

Mission Assignment

This section began by the researchers providing the participants with missions for their characters to complete.

Starting, the participants were more serious and really focused on the missions that were assigned, after a few minutes the lighthearted environment came back.

There was some confusion because the participants were not sure what they were supposed to do .

At this point the participants were really trying to play their character and trying to think about how their characters would deal with that mission.

Given the sexual nature of the workshop, some jokes with sexual innuendos happened for example what participant told another one that they should send a “mensagem picante” (spicy text).

Several times the participants picked up the materials and handled them while trying to think about solutions.

There were some moments of silence but they did not seem provoked by awkwardness or uncomfortableness, the genuinely seemed focused.

Their body language suggested they were really leaning towards each other and working together to address the problems.

The overall participation at this point seemed more rational than emotional, this seemed like it was because of the missions.

Given the intimate topic some participants were scared about intrusion, even asking “quão intrusivo pode ser” (how intrusive can it be).

Although they were exteriorizing their thoughts from themselves for the most part, sometimes they thought how they would personally think “Eu gostava de receber isto” (I would like to receive this).

The characters here were kind of forgotten because the participants didn’t really link this section with their characters.

They often joked about the situations “imagina uma voz tipo alexa a dizer-te “get yourself naked” (picture a voice like alexa telling you “get yourself naked”).

Participant feedback for this section

The feedback was very similar to the first section with a heavy focus on how they enjoyed being provoked.

Last section: Finding the sweet spot

In this section the participants were told to walk through and exposition of explicit anatomical visual materials regarding sexual health and sexual education and then to provide some feedback about the said materials.

Participants tended to talk more with their own gender, male participants discussed male pictures with male participants and the same for female participants, although after sometime this was no longer happening.

They spoke much less during this section.

Some participants were very comfortable with the imagery, someone even said “It’s just a penis!” others not so much, claiming that “It feels quite strange” but the one participant who said that it made them feel strange mentioned that they feel uncomfortable with anatomical depictions, whether they are genitalia or anything else.

Post-notes

Participants appeared comfortable throughout the whole experience, humor was a constant presence in most of the interaction’s participants had between each other, with the researchers or with the provided materials.

When given tasks participants shifter from lighthearted to very serious and focused.

There were a lot of materials which were appreciated by the participants but in some instances, they were very focused on the materials and didn’t think that much outside of them. The materials were very good for allowing the participants to exteriorize themselves from the sensitivity of the topic and from their own awkwardness.

Male participants tended to focus on male subjects and depictions and female participants did the same with female subjects and depictions.

Questionnaire result (post session)



Figure 11 - Feedback from observation 1

I feel like the use of humour helped me feel comfortable

11 respostas

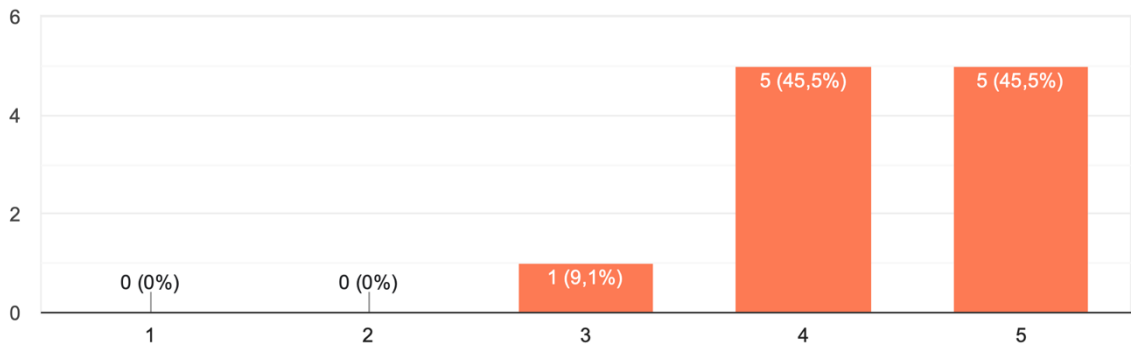


Figure 12 - Feedback from observation 2

I feel like using made up characters and role play helped me feel more comfortable

11 respostas

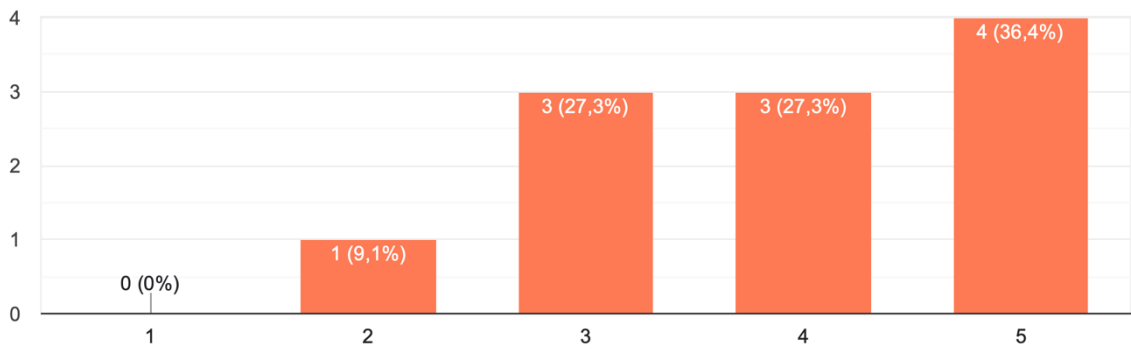


Figure 13 - Feedback from observation 3

I felt overwhelmed by the amount of materials

11 respostas

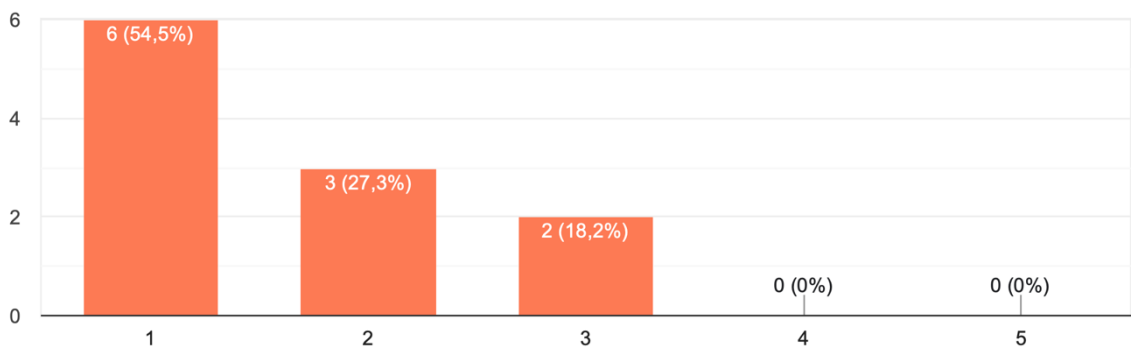


Figure 14 - Feedback from observation 4

I feel like the workshop was too long

11 respostas

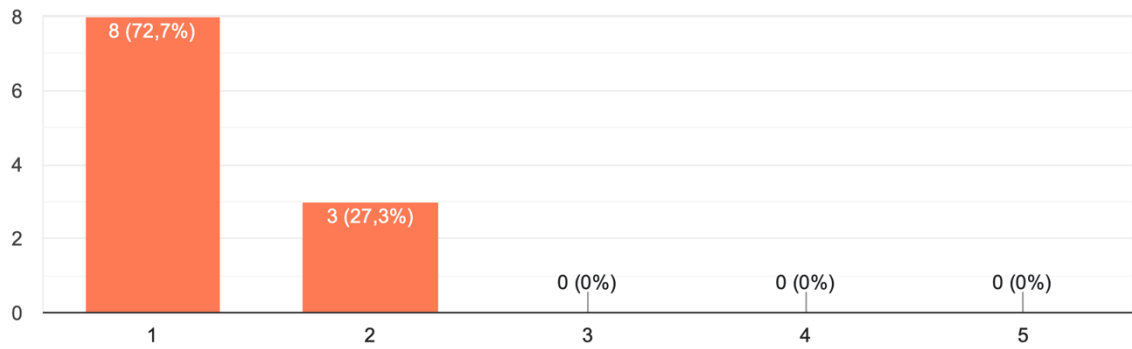


Figure 15 - Feedback from observation 5

I felt comfortable with sharing my experience during the workshop

11 respostas

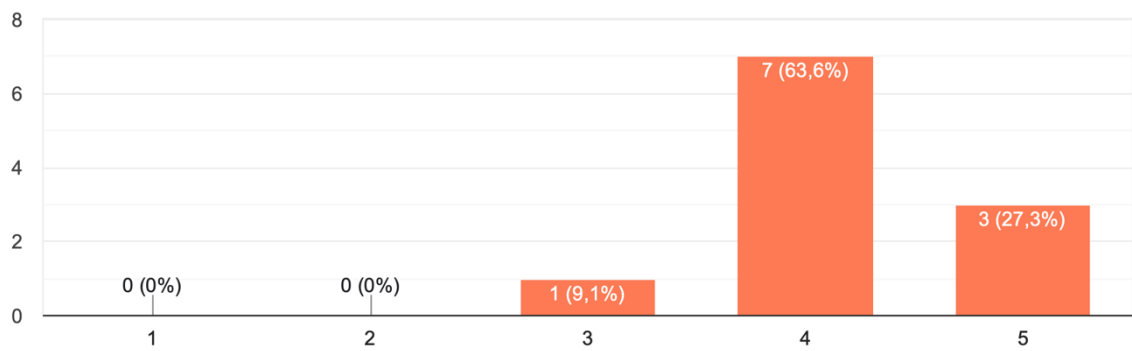


Figure 16 - Feedback from observation 6

I would participate again in similar workshops

11 respostas

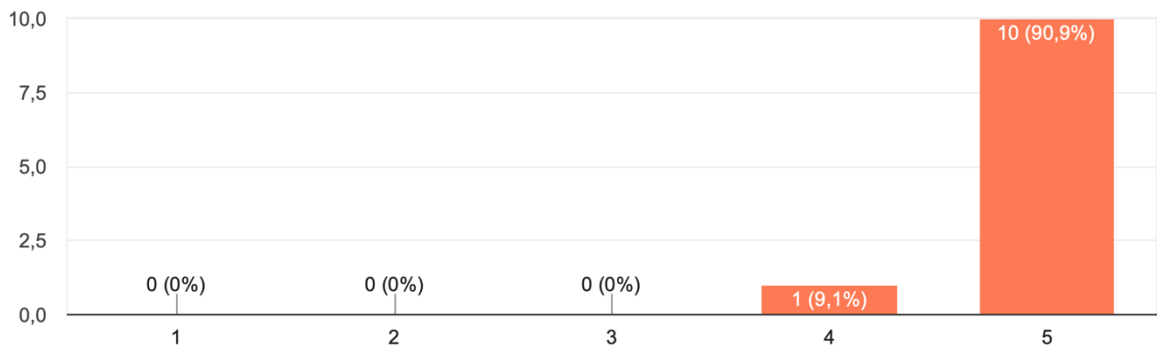


Figure 17 - Feedback from observation 7

Pictures

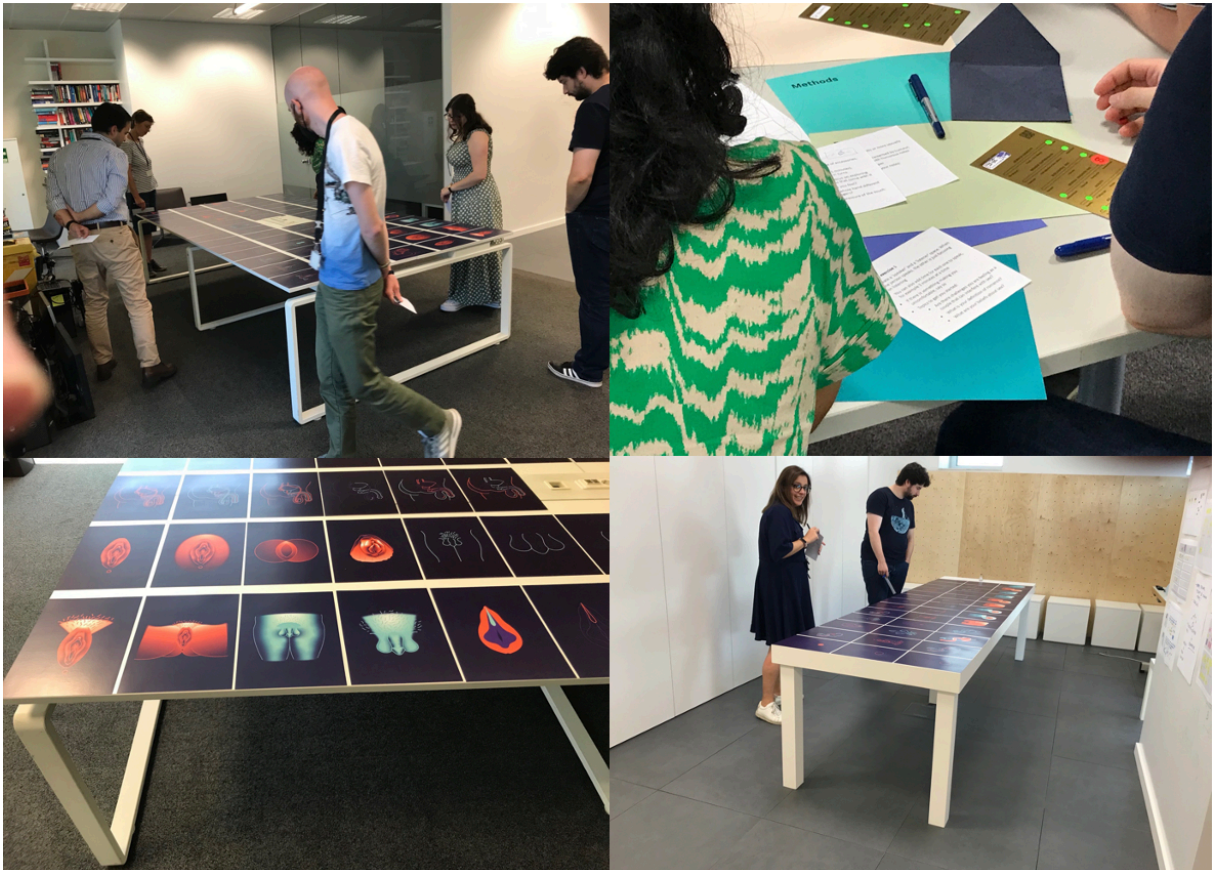


Figure 18 - Pictures from the Observation

APPENDIX D – Focus Groups

Planning

What i want to know:

- How do older adults get to know health products/services
- What is their preferred message delivery, such as tone, language and etc
- What are the channels they use
- What are the criteria for choosing both the channels and the product/service

Consumer behavior in older adults:

- save/invest more;
- spend more on luxury products and services;
- shop during morning hours;
- prefer “one-stop” shopping;
- consider shopping to be a social event;
- are very convenience-oriented;
- patronize reputable/traditional outlets;
- seek personal attention and special services such as valet parking and gift wrapping;
- choose products based on quality and brand name;
- are less price conscious and deal prone;
- use credit as often;
- are as likely to show non-significant responses to sweepstakes and telemarketing;
- complain less when they are not satisfied with something they have bought.

Materials: Several pictures of different outlets of information. Doctor, friends and family, computer, tablet, smartphone and radio

Plan:

- Channels ranking by preference
- Discussion of reasons as to why the ranking was chosen

Brainstorming:

- Utilize opinion leaders seniors enjoy, for example, Dr. Julio Machado Vaz, which was mentioned often. It might be easier to trust technology that reputable professionals recommend instead of going through the new ways of advertising technology such as social media. This might also be the case of using other health professionals or senior “hotspots” such as senior homes, local health stations and maybe hospitals. The key here is building trust, seniors seem very suspicious of technology and a familiar face might help.
- Different segments might build awareness through different means, maybe different levels of education, geographical region, age and financial status might require different approaches. Integrate segmentation through lifestyle choices and experiences might be a good strategy too, it might be good to find a correlation between certain activities and interest in sexual health education.
- One major concern seemed to be the delivery of the message, such as the tone and the language used, with direct and simple deliveries being the preferred ones.

- Multi-level channel approaches might be useful, mixing radio, tv and smartphones for example. The channel of the smartphone might be a good one given the fact that it is supposed to be a mobile platform, it is expected that the seniors already have and know how to operate a smartphone.
- The content should theoretically be simple and provide “reasons why” the service is useful for them and how it improves their life, should be concise and direct.

Literature on older adults and consumer behaviour

“For liking, we found that both age groups liked the emotionally meaningful commercials more than the knowledge related ones, but the difference between the two types of commercials was larger for older adults. Moreover, older adults liked the emotional commercials more than the younger adults did.” (Goot et al., 2016)

“However, the government was considered to be more credible than commercial companies: “that's much more credible than getting it from the Bowflex people who are selling a product.” Many participants mentioned doctors and their governing bodies such as the College of Physicians as the most trusted source for health promotion information.” (Berry et al., 2009)

“The use of celebrity also emerged. For example, participants in one group mentioned an athlete from their town who won an Olympic gold medal in cross-country skiing: “she only appears for seconds... But everybody knows Becky. And in the two or three seconds she's on camera, you relate to that ad.” However, it is important that participants can relate to the celebrity as another participant commented at the suggestion that athletes could be used: “retired hockey players though have done a lot of body building their whole lives. They're not ordinary people.” This prompted several participants to mention that ordinary people such as housewives and farmers would be good to use in such advertisements”. (Berry et al., 2009)

“we found that older people's behavior is more sensitive to their needs and lifestyles, which are in turn influenced by life-changing events and circumstances they experience. We found that segmentation based on these life events and circumstances is more effective than segmentation based on age. This segmentation approach takes into consideration the aging process and the person's life experiences. Simply put, older people who experience similar circumstances in late life are likely to exhibit similar patterns of consumer behavior.” (Moschis, 2003)

Problems with this background research:

- Old research
- Very small quantity
- It is possible that the research might only be applicable to specific geographic regions and to the paper sample

References

Berry, T. R., Spence, J. C., Plotnikoff, R. C., Bauman, A., McCargar, L., Witcher, C., Clark, M., & Stolp, S. (2009). A mixed methods evaluation of televised health promotion advertisements targeted at older adults. *Eval Program Plann*, 32(3), 278-288.
<https://doi.org/10.1016/j.evalprogplan.2009.05.001>

Goot, M. J., Reijmersdal, E. A. v., & Kleemans, M. (2016). The effects of emotional television advertising on older and younger adults. In *Advances in Advertising Research (Vol. VI)* (pp. 115-124). Springer.

Moschis, G. P. (2003). Marketing to older adults: an updated overview of present knowledge and practice. *Journal of consumer marketing*.

Setting and participants

Site: Fraunhofer

Researchers: 1 male and 1 female researcher's

Participants: Minimum age of participants was 55 and they were all Portuguese

Food: Cookies and water

Placement: one table with participants facing each other and the researchers in the edge of the table

Ideation

The main goal of this workshop was to use storytelling and visual materials to gather information regarding the possibilities of technology, particularly mobile apps, dealing with sexual health, what could be done, what were some functionalities that the apps could have that would be good for the participants to use.

The participants were prompted with a story about a distant future where technology was everywhere, even inside people's homes and the said technology could help fix every single health problem that people had. They were given the scenario of an app that could help with sexual health and asked to give some functionalities that could be useful for them.

Materials

Story and related imaged

Let's picture a far away future where technology has already solved most part of the problems that mankind faces, there are apps on their phones that allow people to learn everything about anything.

Mr. Vitor and Mrs. Amélia have been married for the last 40 years and they think they already know everything that is to know about each other, but their intimacy has been a little more complicated the past few years and since they are a couple that does not give up against trouble, they decided to try one of these apps to see if they really are worth anything.

There's also Mr. Arnaldo who's single, growing up he never really learned much about intimacy, he just knew that sex was something that everyone did when the right time came, although no one ever talked to him about it or taught him what it means, now he is single and he wants to learn more about himself and about intimacy, he has already learned that intimacy and sex are two different things. But he wants to keep learning, he wants to look for a new partner and understand how his body works and how he can have a healthy and active sexual life.

What type of problems do you think these people face in their daily lives?

How can an app help these people to solve their problems and move towards a healthy sexual life?



Figure 19 - Allusive Pictures for the story

Discussion Pictures



Figure 20 - Visual Materials for ideation

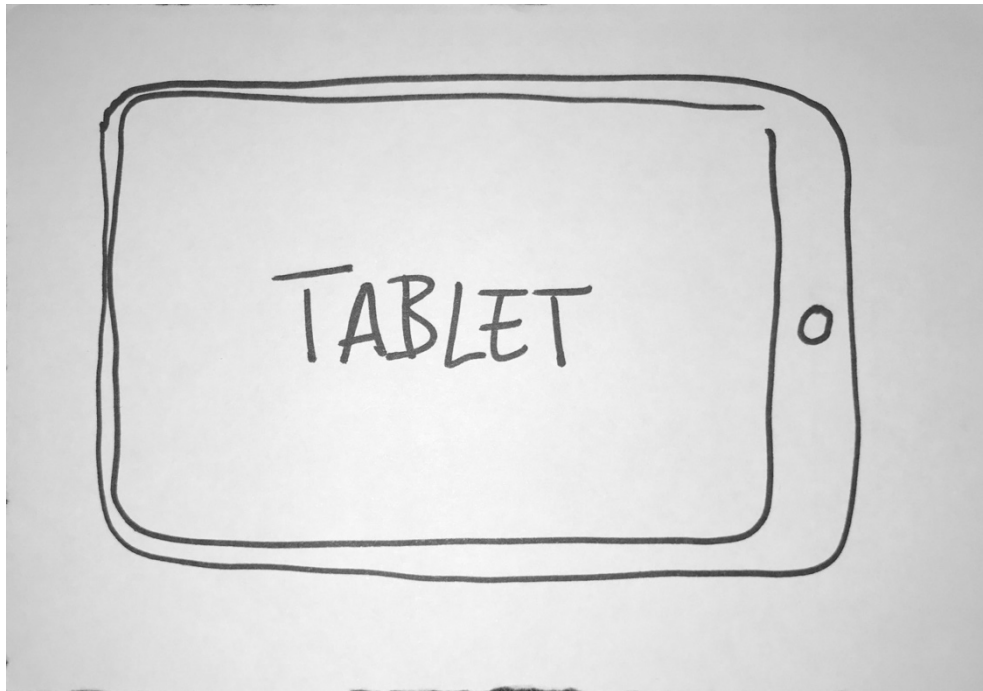


Figure 21 - Low fidelity drawing used when participants shared they used something that was not on the materials

Section 1

In the first stage of the workshop two stories were read regarding three older adults, composed of two couples and a widow, the main problematic of the story was the same, problems associated with sexual health and old age, but there were some particularities to each case given the fundamental differences of life of a married couple and a widow. It was also given some allusive pictures of a couple and an individual man, so that participants had something to hold and associate with the story.

Notes for section 1

The story was a good starting point so the participants could start talking about the problem at hand, starting by giving their personal opinions without having to share their personal experiences. This was possible because they spoke from the participants point of view. After a while they indeed started talking about their own experiences and talking in the first person, sometimes using euphemisms to address particular subjects. In this section now awkwardness was found, and the participants seemed comfortable with each other and sharing their experiences, although one of the participants felt uncomfortable with the subject in general because of the way they were raised and because of their relationships in their life, in the end the participant ended up sharing their experience anyway.

Section 2

At this stage, the participants were given a series of visual materials depicting different ways to convey information, such as doctors, radios, tablets, phones, computers etc.. and asked to order them from least favorite to favorite way of gathering health education.

Notes from section 2

The participants spent a good amount of time looking at the pictures and changing order as they thought.

Some participants instead of ordering the pictures constructed a train of thought from the pictures such as “First i start searching for information online, then i discuss it with my friends and family and then finally I’ll bring it to the doctor”, which suggested that having steps to follow was easier than to just go somewhere and accept it.

Feedback questionnaire

All of the following statements where evaluated using a linear scale ranging from 1 (totally disagree) to 5 (totally agree), no names of participants were associated with the their answer sheet therefore the results are anonymous.

Senti-me confortável durante a experiência

4 respostas

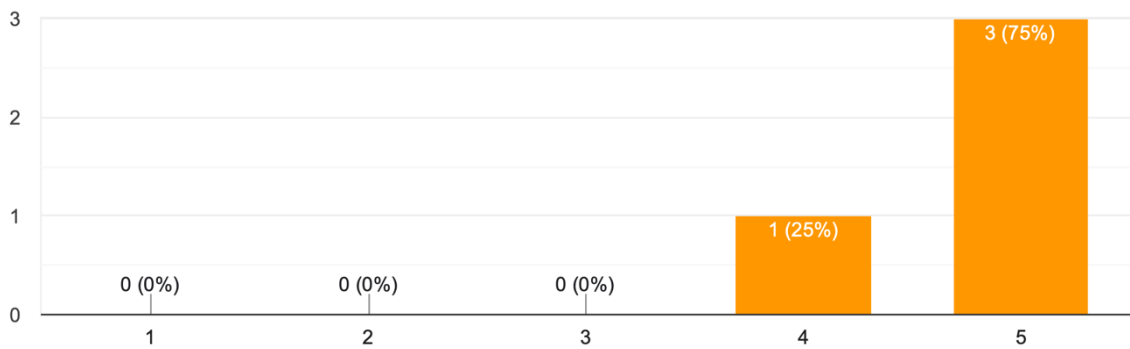


Figure 22 - Feedback from Ideation 1

A experiência foi desafiante

4 respostas

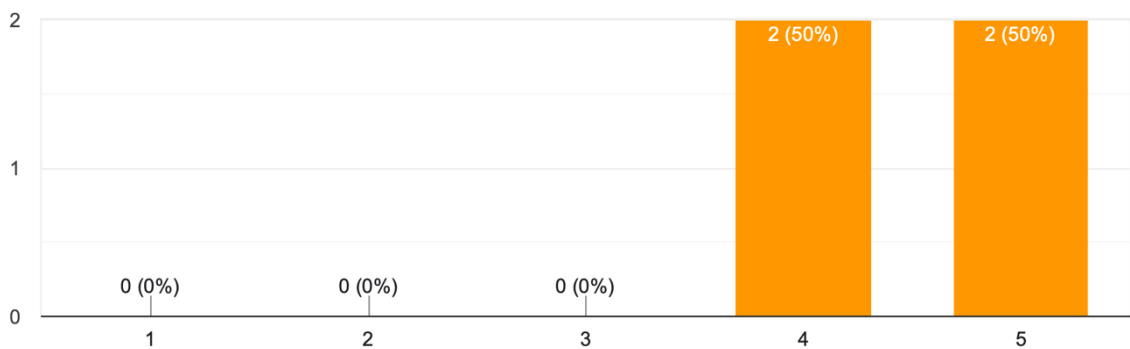


Figure 23 - Feedback from Ideation 2

Tive dificuldade em responder ao que era pedido

4 respostas

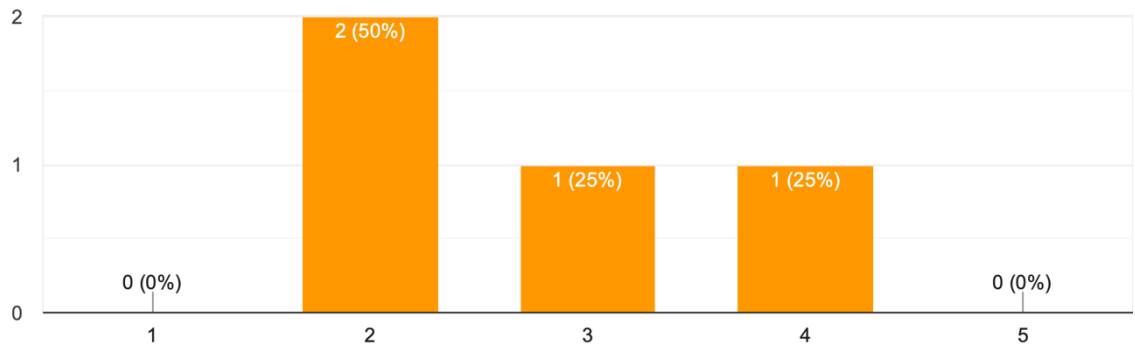


Figure 24 - Feedback from Ideation 3

A história foi cativante

4 respostas

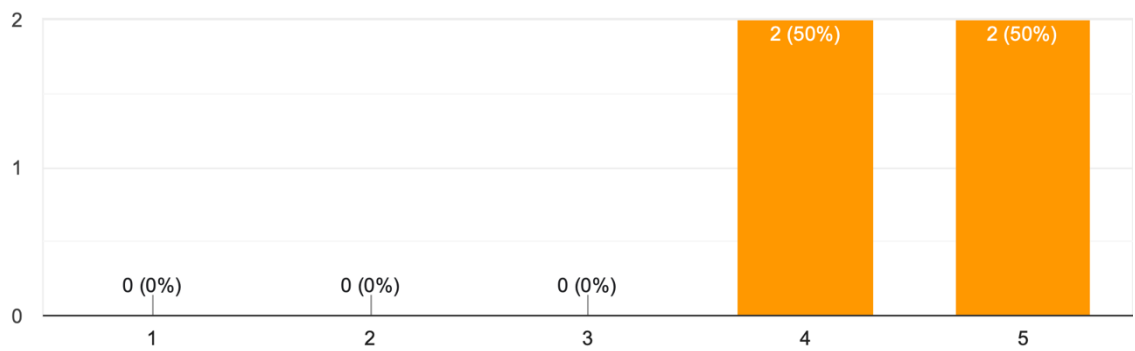


Figure 25 - Feedback from Ideation 4

Senti-me bem a ser criativo

4 respostas

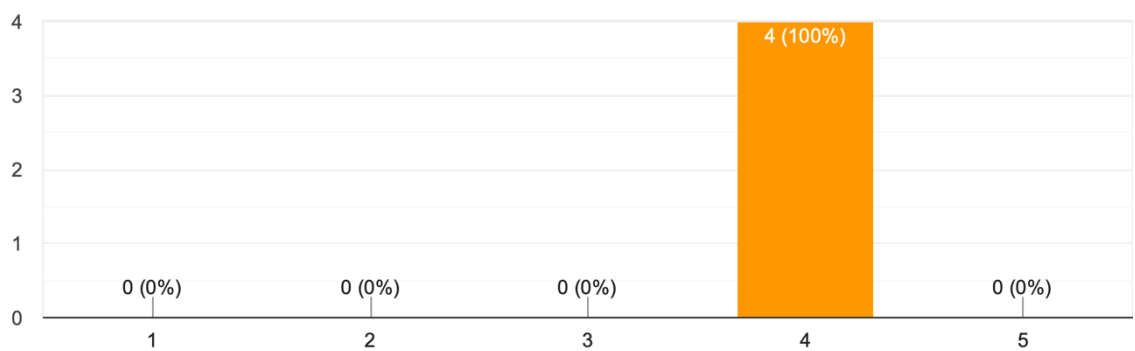


Figure 26 - Feedback from Ideation 5

Repetiria esta experiênci

4 respostas

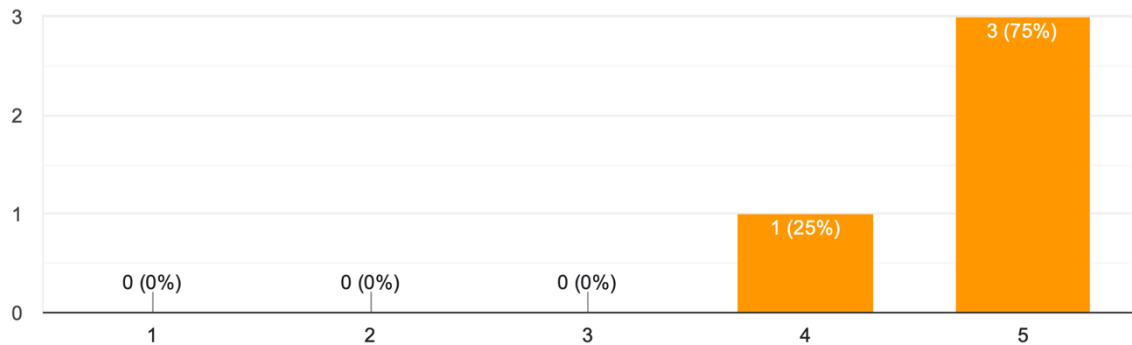


Figure 27 - Feedback from Ideation 6

Results for the methodology evaluation

The use of utopian ideation was not very effective with this demographic because the subject of ideation was technology, participants were not sure on what to imagine and how to innovate, it is suspected that this happened because of the perceived lack of technological literacy, this also was reflected on the questionnaires with some participants saying they had some trouble answering to what was asked.

Participants held on to technology they already knew and focused heavily on the functionalities of the said technology, for example voice-assistants in smartphones.

The use of the story was a good starting point although the participants quickly forgot about it and moved on to talk about the subject without mentioning the story.

It seemed like the participants enjoyed having the pictures to hold while they spoke.

It was curious to see that some participants when asked to create an order from favorite to least favorite mean of searching for information, instead of creating the order, more than one participant instead created a train of information gathering starting from point x until point y, usually ending with a conversation with their doctor.

There was a lot of sharing of personal experiences, even some that were unprompted, and it didn't seem like the participants were having any trouble sharing them.

Awareness subtle stigma

Following the results from the first workshop, it was decided that the story would be removed since it didn't carry a significant effect on the participants. The participants were given the same pictures from the first workshop with an addition of a tablet, because some of the participants said that it was something they often used. In this workshop the stigmatizing topics will be approached subtly beginning with prompts to talk about health in general only later addressing sexual health and intimacy.

Visual Materials

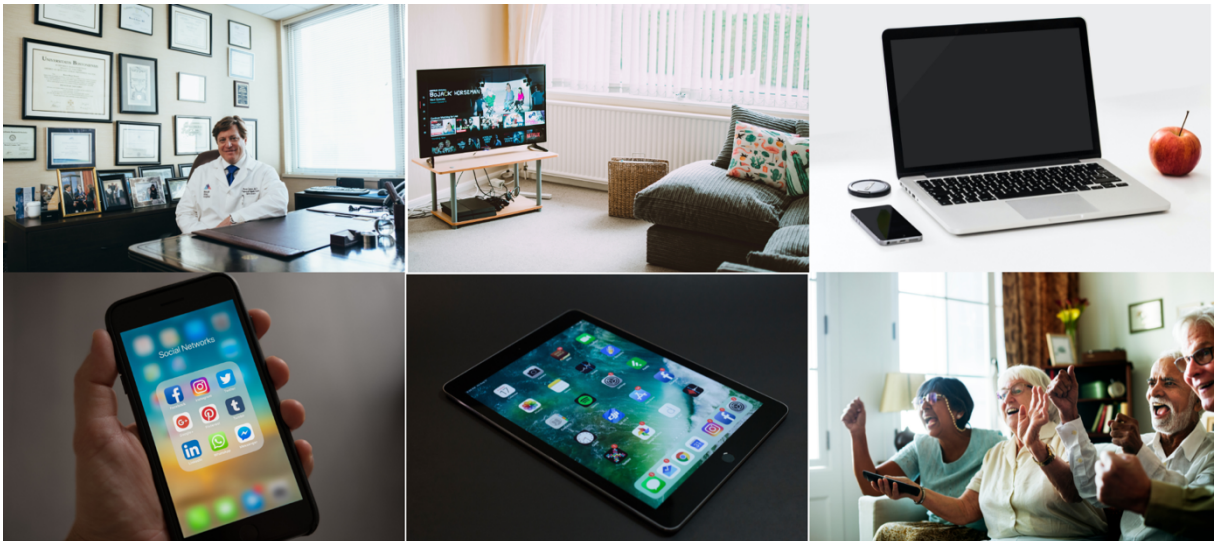


Figure 28 - Visual Materials for both Awareness workshops

Feedback Questionnaire

Prefiro que a comunicação seja

3 respostas

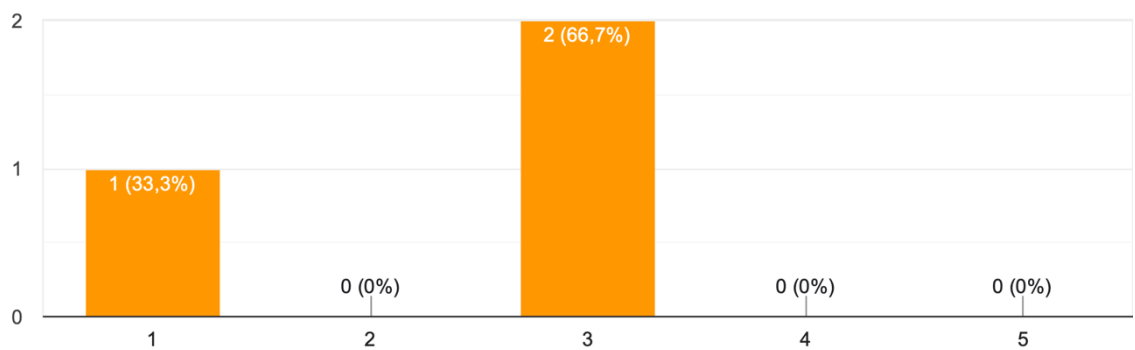


Figure 29 - Feedback from Awareness 1

Gosto que a comunicação seja

3 respostas

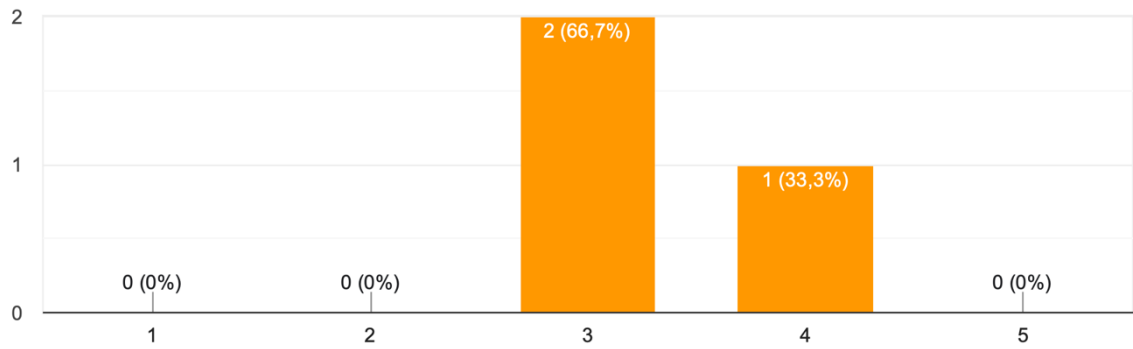


Figure 30 - Feedback from Awareness 2

A mensagem deve ser

3 respostas

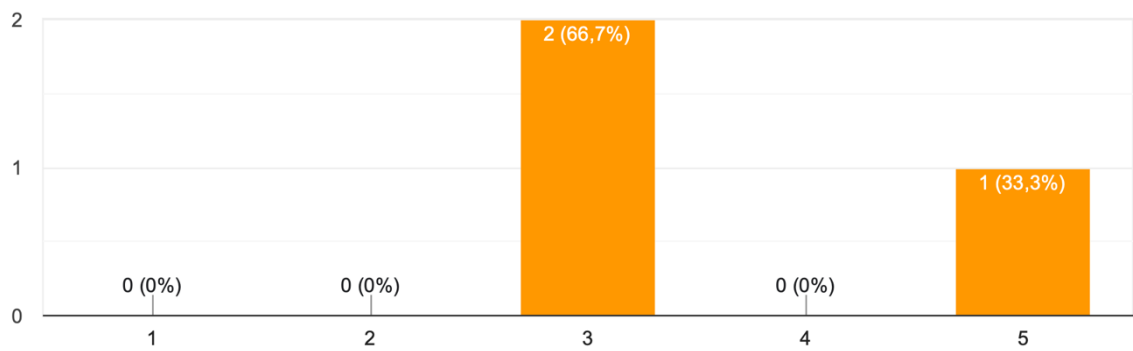


Figure 31 - Feedback from Awareness 3

Prefiro que a comunicação seja

3 respostas

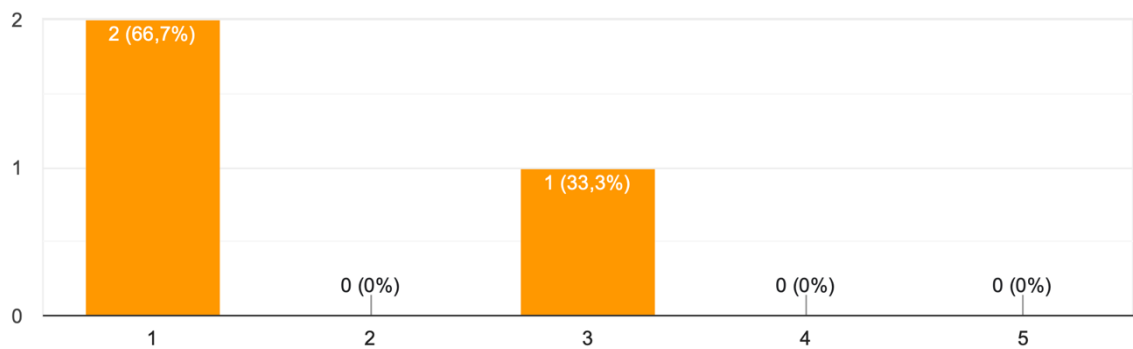


Figure 32 - Feedback from Awareness 4

Prefiro

3 respostas

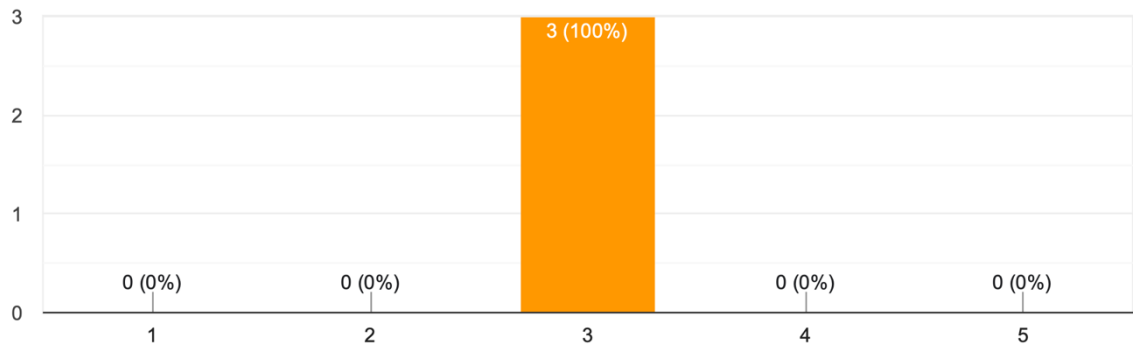


Figure 33 - Feedback from Awareness 5

Mensagem

3 respostas

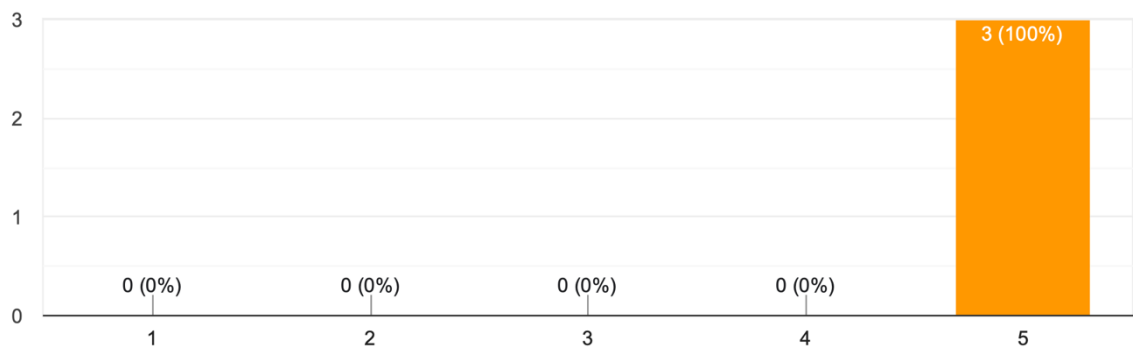


Figure 34 - Feedback from Awareness 6

Meio de comunicação

3 respostas

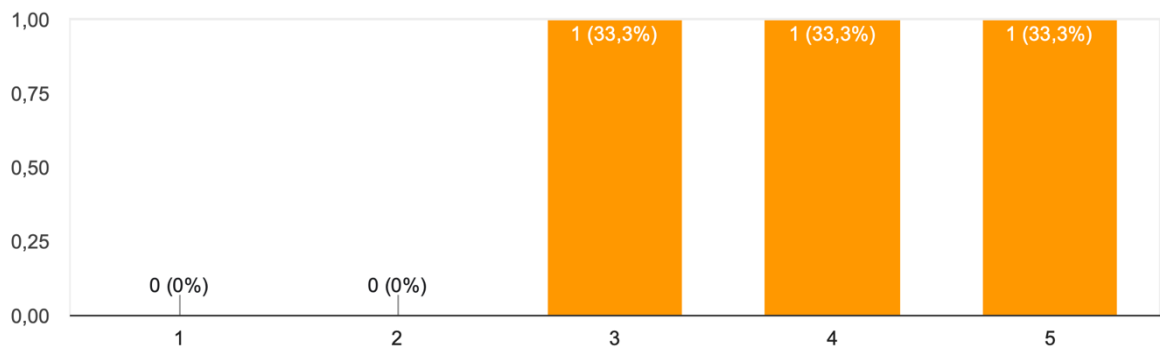


Figure 35 - Feedback from Awareness 7

Confio na Televisão

3 respostas

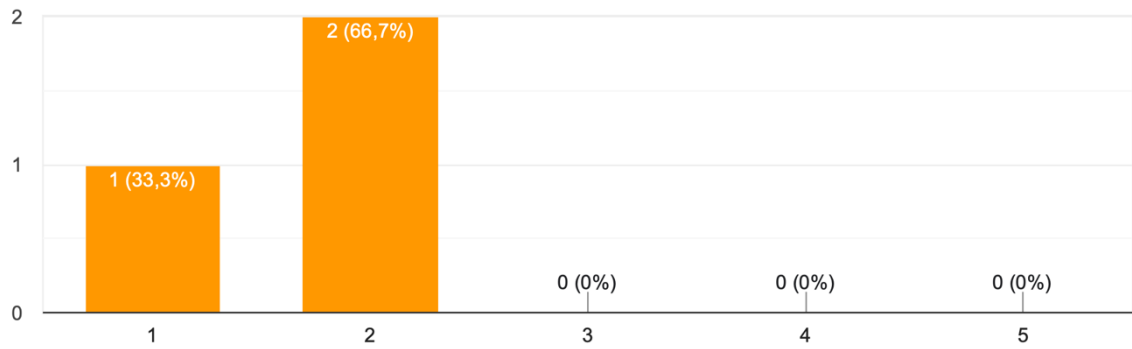


Figure 36 - Feedback from Awareness 8

Confio no Computador

3 respostas

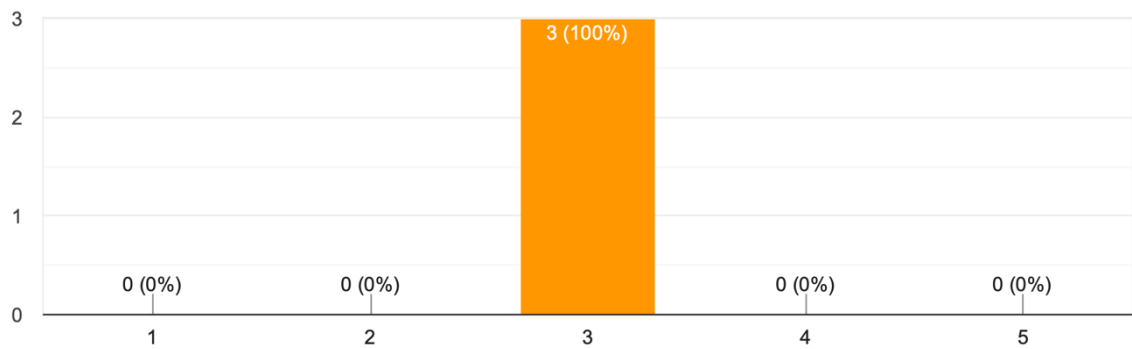


Figure 37 - Feedback from Awareness 9

Confio no telemóvel

3 respostas

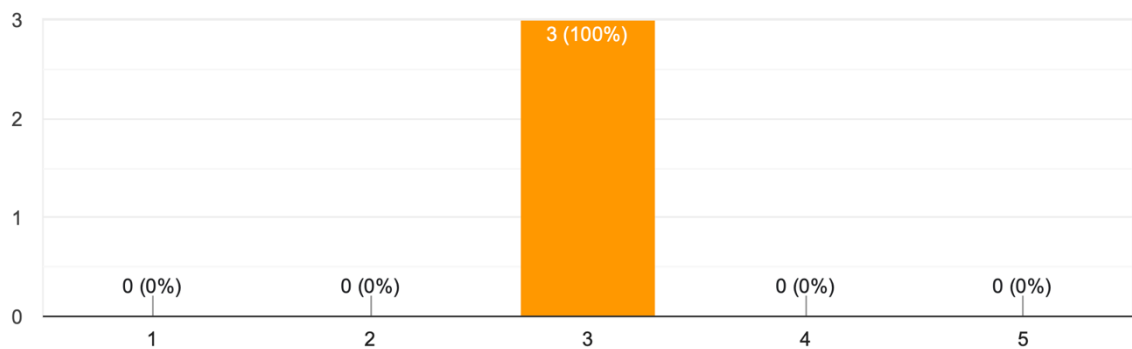


Figure 38 - Feedback from Awareness 11

Confio no médico
3 respostas

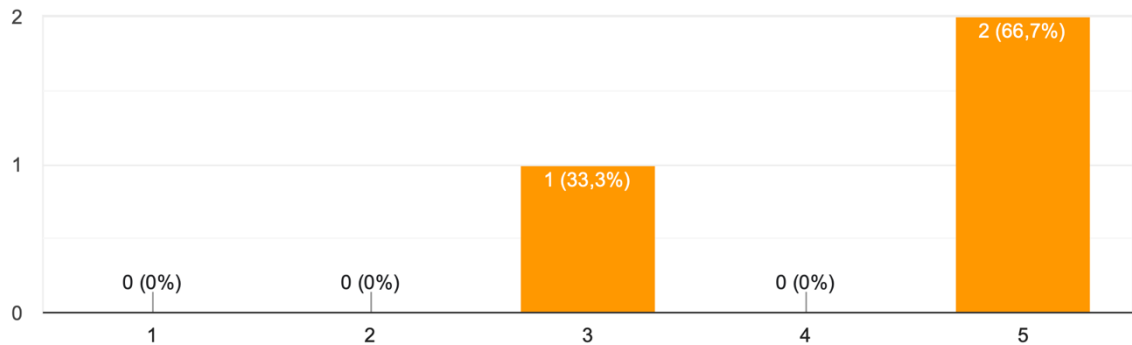


Figure 39 - Feedback from Awareness 10

Results for methodology evaluation

The findings were quite similar to the ones previously gathered in the Ideation workshop. Having visual materials, they could interact with was something that was appreciated, even when discussing things with the other participants and with the researcher’s participants really made use of pictures to help convey their messages.

At one point it seemed like it was a good decision to have researchers from both genders present because the themes of intimate health and hygiene arose, and the female participants directed their full attention to the female researcher and the male participant directed his focus to the male researcher.

The participants seemed comfortable during the whole session and there were no conflicts between participants.

During the discussion some political themes came forward, such as the patriarchy and the need to give power to women, but the participants discussed it without conflict, it is hard to remove the political and societal undertones from stigmatizing topics.

Awareness stigma present

The third and final workshop took the same materials as the previous one but with one key change, instead of addressing the stigmatizing topic subtly, the topic will be brought up from the start in order to expose the participants to the stigma.

Feedback Questionnaire

All of the following statements were evaluated using a linear scale ranging from 1 (totally disagree) to 5 (totally agree), no names of participants were associated with the their answer sheet therefore the results are anonymous.

Senti-me confortável durante a experiência

3 respostas

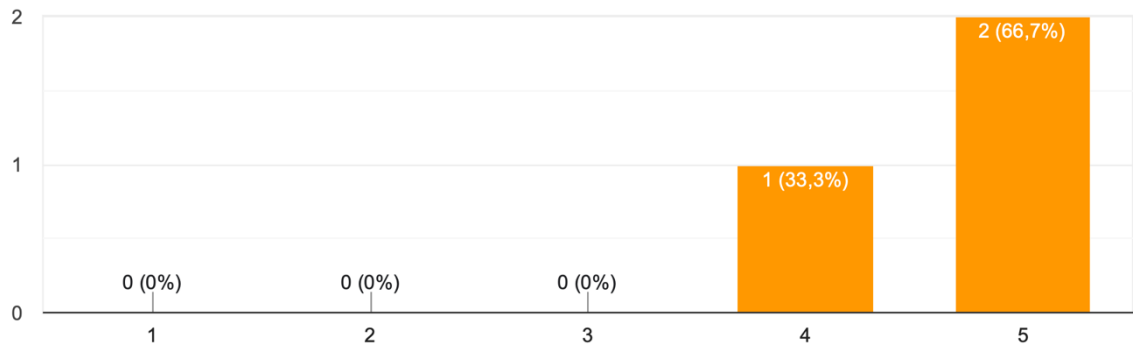


Figure 40 - Feedback from Awareness Stigma 1

A experiência foi desafiante

3 respostas

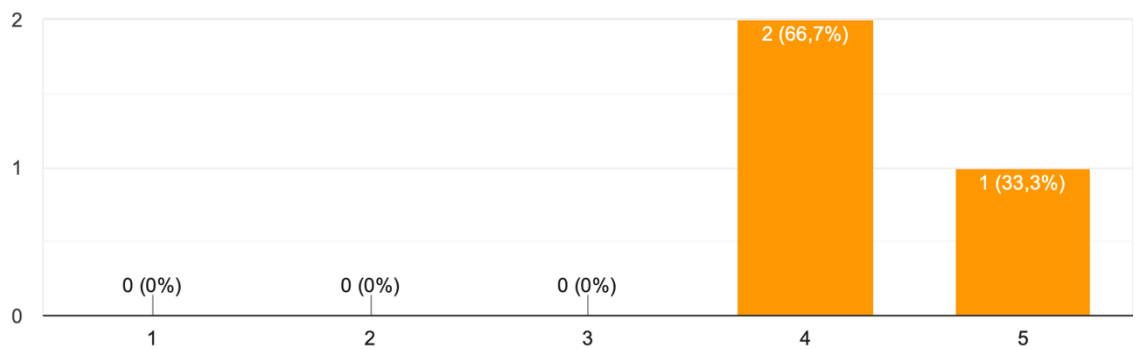


Figure 41 - Feedback from Awareness Stigma 2

Tive dificuldade em responder ao que era pedido

3 respostas

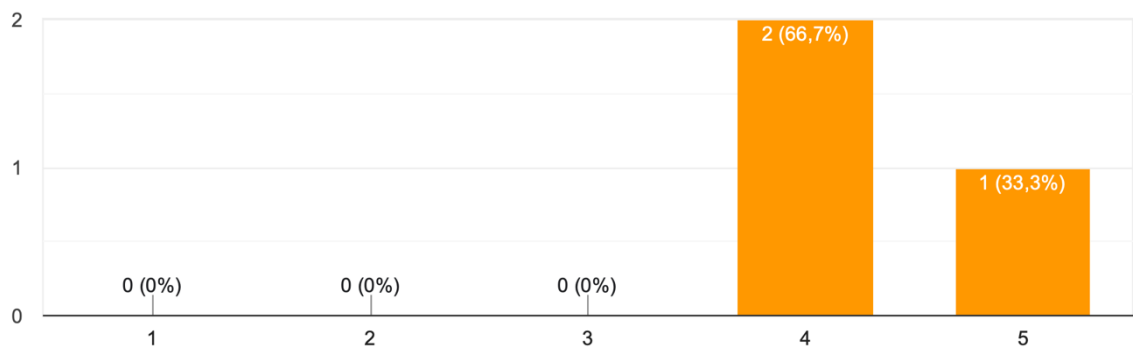


Figure 42 - Feedback from Awareness Stigma 3

Senti-me bem ao contribuir para a investigação

3 respostas

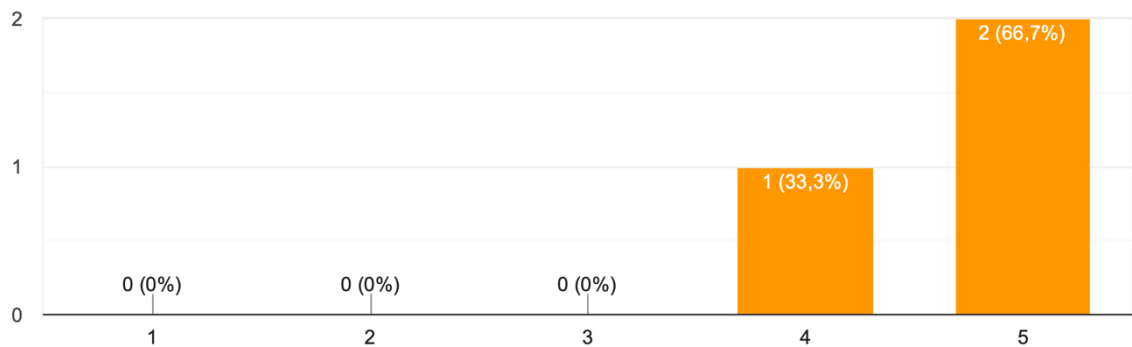


Figure 43 - Feedback from Awareness Stigma 4

Repetiria esta experiência

3 respostas

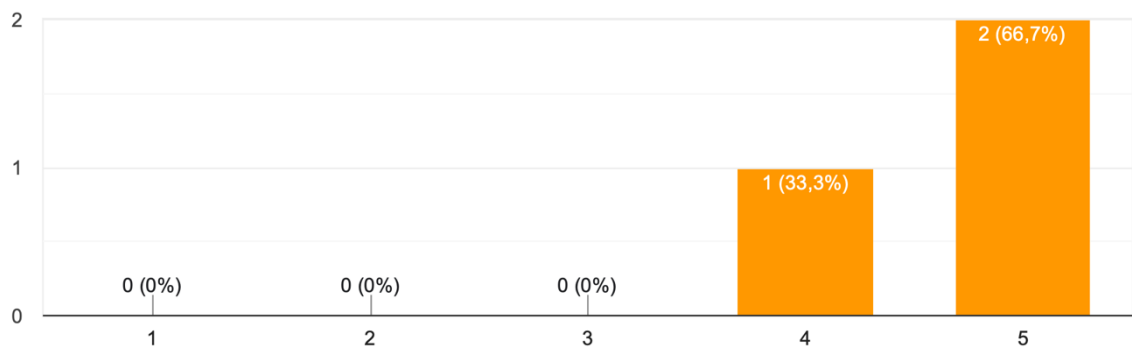


Figure 44 - Feedback from Awareness Stigma 5

Results for methodology evaluation

It was observed again that the participants tend to discuss more sensitive subjects, such as STD's, hygiene, and sex with the researchers of the same gender as them.

One participant felt notoriously uncomfortable when discussing sexually charged topics, avoiding the conversation, and shifting in their chair, it was possible that this was caused by one of the other participants being a family member.

The habit of building a train of information with the pictures instead of ordering them by preference was again seen.

At one point the subject of sexual preference came up and two participants had very opposing views of the subject which prompted a heated exchange of words between the too, it was easily controlled, and it showed no signs of affecting the remainder of the session.

Again, the use of humor was a constant, the participants tended to make jokes when discussing difficult topics such as sex, one example, was that when sharing sexual experiences with their partners humor was very often used.

Participants enjoyed knowing they were being helpful not only to the society but to the researchers as well.

Artistic outlets were sought from one of the participants using the given paper and pen to draw the figure of a woman to help convey the message.



Figure 45 - Pictures from the focus groups